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ORIGINAL PAPER

Caregiving Attitudes, Personal Loss, and Stress-Related Growth Among Siblings of Adults with Mental Illness

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Abstract As parents age, well siblings are often asked to assume caregiving responsibilities for their brother or sister with mental illness. However, relatively little is known about how well siblings prioritize sibling caregiving responsibilities with other life demands. We examined well siblings' attitudes toward self-care and caregiving for their sibling with mental illness (self- and sibling-care) using two cross-sectional samples. The first sample of well siblings ($N = 242$) was used to examine the psychometric properties of the self- and sibling-care measure (SSCM), designed to assess the degree to which siblings prioritize their own needs and the needs of their sibling with mental illness. A second sample ($N = 103$) was used to determine the relative contribution of self- and sibling-care attitudes in accounting for variation in well siblings' reports of personal loss and stress-related personal growth. Results support the psychometric validity of the SSCM and suggest that self- and sibling-care attitudes account for greater variance in scores on perceived personal loss and stress-related growth than demographic or caregiving factors. Our findings support the need to address family care responsibilities and resource limitations through recovery-oriented mental health policies, services, and programs.

Keywords Sibling · Caregiving · Serious mental illness · Family · Ambivalence

Introduction

The mental health care system in the United States has struggled to provide adequate support services to adults with psychiatric disabilities (Sartorius et al. 2004). As a result, family members often represent the main source of care for their relatives with mental illness (Lively et al. 2004). Although parents usually take the lead in efforts to care for adult children with serious mental illness, siblings often assume caregiving responsibilities when parents are no longer able to provide care (Cummings and Kropf 2011; Pillemer and Suitor 2014).

Serious mental illness usually emerges in adolescence or young adulthood in the context of a mental health crisis, which requires siblings to adjust to their brother's or sister's behavioral changes and to associated changes in family relationships (Sin et al. 2008; Taylor et al. 2008). The treatment and support needs of siblings with mental illness often take away from parental investment of time and resources to their other children, sometimes across the adult lifespan, and place these siblings at risk for undesirable life course outcomes (Hatfield and Lefley 2005; Jewell and Stein 2002). For example, in a recent longitudinal study, adults who had a sibling with serious mental illness generally completed fewer years of education and were twice as likely to be unemployed in the early years of midlife when

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compared to adults with non-disabled siblings (Wolfe et al. 2014). For the past two decades, the term "well sibling" has been used by researchers to refer to siblings who provide caregiving to a brother or sister with serious mental illness but do not meet diagnostic criteria for a major mental illness themselves (Abrams 2009; Greenberg et al. 1997; Marsh and Dickens 1997). However, given that mental illness often runs in families, the term "well sibling" does not necessarily mean that these siblings do not face their own mental health issues (Leith and Stein 2012).

Several studies that compare well siblings of adults with psychiatric disabilities to siblings without psychiatric disabilities provide compelling evidence of the challenges faced by well siblings. Findings from a 46-year longitudinal study comparing 83 well siblings of adults with serious mental illness to non-affected sibling pairs showed that well siblings of adults with mental illness reported greater psychological distress and less psychological well-being than non-affected siblings (Taylor et al. 2008). In a comparison study of 329 well siblings of adults with intellectual disability and 61 well siblings of adults with serious mental illness, siblings of adults with intellectual disabilities were significantly more likely than siblings of adults with mental illness to report greater psychological well-being, closer patterns of contact, and a closer relationship with their sibling (Seltzer et al. 1997). In contrast, well siblings of adults with serious mental illness generally reported better psychological well-being when they felt that the impact of their ill sibling on their own lives was limited.

Research also points to psychosocial losses associated with having a sibling with serious mental illness (Lohrer et al. 2006; Stålberg et al. 2004). Personal loss due to mental illness, or the subjective experience of loss due to both psychiatric disability and a lack of access to valued social roles, has been studied in both individuals with serious mental illness and their family members (Baker et al. 2009; Stein et al. 2005; Stein and Wemmerus 2001). Leith and Stein (2012) found that self-reported personal loss among well siblings was the strongest predictor of current caregiving for a brother or sister with mental illness, even after accounting for the significant contribution of age, support group affiliation, and level of sibling dependence. Other studies of well siblings of adults with mental illness showed that perceived caregiving responsibilities were associated with poorer psychosocial functioning, increased burden, insufficient engagement in self-care, and lowered ability to meet adult role expectations (Jansen et al. 2015; Taylor et al. 2008).

These findings highlight the importance of self-care among well siblings who contend with family caregiving responsibilities for their brother or sister with a psychiatric disability. Self-care refers to actions that are taken to recover, maintain, or improve one's own physical and emotional health and well-being (Zigarus 2004). Among well siblings of adults with serious mental illness, self-care priorities involve placing greater emphasis on one's own physical, emotional, financial, or familial needs (Jewell 1999) rather than on sibling needs. Poor sibling relationship quality during childhood and adolescence and differential treatment by parents can decrease well siblings' willingness to engage in caregiving in adulthood despite sociocultural or family expectations (Jewell and Stein 2002; Smith et al. 2007). Well siblings' family and career responsibilities and the financial and psychological burdens associated with providing sibling care may compel well siblings to focus on their own needs (Bauer et al. 2012). In placing limits on their engagement in caregiving, well siblings may be better able to conserve their energy and renew their ability to provide family support when it is most needed (Lashewicz et al. 2012).

Although preferences toward self-care are understandable and may be adaptive in many ways (Acton 2002; Marsh et al. 1996), studies of family caregiving suggest that prioritizing one's own needs is often associated with ambivalence and guilt (Schmid et al. 2009; Waite-Jones and Madill 2008). Given the tension between individual needs for self-care and societal or familial expectations for caregiving, some siblings strive to find a balance in their self-care and sibling-care commitments while others struggle to resolve ambivalence about how to negotiate self-care and sibling caregiving roles (Acton 2002; Jewell and Stein 2002). Although the concept of ambivalence in sibling caregiving has been examined in case studies or samples of siblings with developmental disabilities (Lashewicz et al. 2012; Waite-Jones and Madill 2008), it is unclear what role, if any, ambivalence plays in well siblings' psychosocial and psychological functioning.

In contrast to ambivalence and self-care priorities, some well siblings strive to balance personal needs and the needs and welfare of their siblings with mental illness (Jewell 1999). Many well siblings choose to provide support and assistance to their sibling with mental illness, particularly when the pre-illness sibling bond is characterized by strong emotional ties (Stålberg et al. 2004). Although psychological distress, personal loss, and subjective and objective burden have commonly been associated with providing care to a relative with mental illness (Bauer et al. 2012), studies of personal gains and stress-related growth suggest that individuals also report positive changes as a result of dealing with challenging life circumstances (Chen and Greenberg 2004; Joseph and Linley 2006). Family members have reported deriving a sense of personal growth from caring for a loved one with mental illness that can include increased empathy and understanding, better coping skills, greater closeness within their family of origin, and involvement in mental health and social advocacy efforts

(Pearce et al. 2015; Sanders and Szymanski 2013). In a study of parental caregivers, Aschbrenner et al. (2014) found that parents who provided greater daily assistance to their adult children with mental illness reported greater personal growth than parents who were less involved in caregiving. Currently, it is unclear if well siblings who provide care to their brother or sister with mental illness report similar growth experiences.

Prior research has also highlighted the role of demographic and situational factors on caregiving behaviors and attitudes among family members. Although women are generally involved in more family caregiving activities than men (Greenberg et al. 1997), findings are mixed with regard to the role of gender in sibling caregiving (Horwitz et al. 1992; Orsmond and Seltzer 2000; Pinquart and Sörensen 2006; Smith et al. 2007). Situational factors, such as being married, having children of one's own, and geographical distance from one's family of origin have been characterized as barriers to caregiving by well siblings (Greenberg et al. 1999; Hatfield and Lefley 2005; Marsh 1998). Prior research has also shown that support group affiliation, such as membership in the National Alliance for Mental Illness (NAMI), is generally associated with higher levels of current and future intentions to provide care to siblings with mental illness (Aschbrenner et al. 2014; Chen and Greenberg 2004).

The onset of serious mental illness interrupts normative life stages among family members while also providing opportunities for building on family strengths (Aschbrenner et al. 2014; Stein and Wemmerus 2001). Prior research suggests that both personal loss and stress-related growth may be central experiences of family members of individuals with serious mental illness (Lohrer et al. 2006; Stein et al. 2005). The personal loss construct captures responses to unwanted or unexpected changes in identity and future roles, routines, and aspirations as a result of mental illness (Stein et al. 2005). Studies of stress-related growth have shown that adults can reinterpret difficult circumstances such as caregiving responsibilities as positive opportunities for meaning making and self-development (Chen and Greenberg 2004; Chen and Lukens 2011). Well siblings' caregiving priorities may be an influential factor in how siblings cope with the losses associated with the sibling role and their efforts to derive a sense of growth from difficult life circumstances.

Based on existing literature in family caregiving, self-care, and coping with mental illness, the self-and-sibling care measure (SSCM) was developed in the present study and its psychometric properties were examined in Study 1. Using a sample of 242 adult well siblings, we examined structural characteristics of the SSCM and the relationship of SSCM scores to demographic characteristics and to scores on measures of current caregiving, intentions to provide care, caregiver burden, interaction guilt, and family satisfaction. We hypothesized that Study 1 would support the construct validity of the SSCM. Using a separate sample of 103 adult well siblings, Study 2 used the self-and-sibling care measure to examine substantive issues related to the well-being of adults coping with their sibling's mental illness. Specifically, we examined the relative contribution of scores on the SSCM in accounting for variation in well siblings' reports of personal loss and stress-related personal growth related to having a sibling with mental illness. We hypothesized well siblings' reports of self- and sibling-care attitudes would account for greater variation in their reports of personal loss and stress-related growth than demographic characteristics and measures of sibling caregiving.

Study 1

Method

Participants

A national sample of 242 adult well siblings (44 men and 198 women) who endorsed having a sibling with a serious mental illness (as defined by the American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders-IV-TR, 2000) were recruited for Study 1. A subset of sample demographics can be found in Table 1. A majority of the sample participants were Caucasian (87.6%), with an average age of 40.7 years (SD = 9.8). Approximately one-half (52.5%) of participants were married or living with a domestic partner. Over half (57.4%) reported having no children. Many participants were also educated beyond high school, reporting that they had completed "some college" (30%) or "a 4 year college degree" (48%). Most participants either self-identified as Protestant or Catholic (52%) or as having no religious affiliation (23%). Sixty percent of well siblings reported affiliation with a support group for family members of individuals with mental illness, such as the National Alliance on Mental Illness (NAMI).

When asked about their involvement in the life of their sibling with mental illness, 21% of well siblings reported that they are the "primary caregiver," or the family member who feels most responsible for making sure their sibling is managing their illness. About one-third (31%) reported "a moderate or a great amount of responsibility" for taking care of their ill sibling, and 30% reported "no responsibility" for caretaking. Nearly two-thirds (59%) of participants reported that they felt "moderately" to "very" close to their sibling with mental illness. A total of 42% of well sibling respondents reported living within an hour drive of their sibling

Table 1 Participant characteristics for study 1 and study 2

Study 1		Study 2	
$N = 242$	Number (%)	$N = 103$	Number (%)
Gender		Gender[a]	
Male	44 (18.2)	Male	22 (21.4)
Female	198 (81.8)	Female	81 (78.6)
Mean age[a]	40.7 (9.8)	Mean age	38.9 (13.8)
Ethnicity[a]		Ethnicity	
European American	212 (87.6)	European American	93 (90.3)
Other	40 (16.5)	Other	9 (8.7)
Marital status[a]		Marital status	
Married/living with partner	127 (52.5)	Married/living with partner	54 (52.4)
Single/never married	90 (37.2)	Single/never married	37 (35.9)
Divorced/separated/widowed	25 (10.3)	Divorced/separated/widowed	11 (10.7)
Current income[a]		Current income[a]	
Less than $20,000	46 (19.3)	Less than $20,000	28 (27.2)
$20,000–49,000	103 (43.3)	$20,000–49,000	31 (30)
$50,000+	89 (37.4)	$50,000+	35 (34)
Education[a]		Education	
Some high school	8 (3.3)	Some high school	2 (1.9)
High school graduate	44 (18.2)	High school graduate	4 (3.9)
Some college	73 (30.2)	Some college	31 (30)
Bachelors	116 (47.9)	Bachelors	33 (32)
Advanced degree	1 (0.4)	Advanced degree	33 (32)
Number of children[a]		Number of children[a]	
None	139 (57.4)	None	51 (49.5)
1	34 (14.0)	1	11 (10.7)
2	44 (18.2)	2	19 (18.4)

[a] Indicates missing data for two or more individuals

with mental illness, and the remaining 58% of the sample reported living more than 1 hour away.

In Study 1, a majority (67%) of participants reported that their sibling with mental illness was male (67%), with a mean age of 40 years (SD = 8.94). A majority (77%) of participants' siblings were reportedly diagnosed with schizophrenia or schizoaffective disorder. About one-third (31%) of the sample reported that their sibling was diagnosed between 10 and 20 years ago, and 37% reported that their sibling has been diagnosed for over twenty years. Most siblings with mental illness were reportedly single (78%) or separated/divorced (14%). Participants also reported that their siblings with mental illness were living with a family member (23%) or living independently with no formal supervision (45%).

Procedure

After receiving approval for the research from the Institutional Research Board of a Midwestern university where the study was conducted, individuals were invited to participate in the study through announcements placed in national and state newsletters published by NAMI and through telephone contacts with support group facilitators and leaders of state chapters of NAMI who assisted recruitment efforts by sharing study announcements with their members. We sent questionnaires to interested individuals who completed and returned them via US mail. Each questionnaire was assigned a code number before distribution and all questionnaires were completed confidentially. Completing and returning the confidential questionnaire was an indication that participants gave their informed consent to participate. A total of 467 questionnaires were distributed and 257 were returned, a response rate of 55%. A total of 242 questionnaires were valid for inclusion in the present study, with 15 considered invalid because respondents indicated they had more than one sibling with severe mental illness or their sibling was no longer living.

Measures

Self- and sibling-care measure The Self- and Sibling-Care Measure (SSCM) is a 16-item self-report measure designed to assess the extent to which well siblings prioritize their personal needs over the needs of their sibling with mental illness. We developed an initial set of 38-items based on conversations with well siblings and findings from a qualitative study of 111 adult well siblings (Jewell and Stein 2002). Based on themes derived from these qualitative interviews, the items reflected a priority toward self-care ("self-care priorities"), a balance in self- and sibling-care ("balanced sibling-care priorities"), and ambivalence toward sibling caregiving ("ambivalence"). Twenty items were initially eliminated due to redundancy and unclear wording. The 18-item measure that remained was piloted on a small sample of well siblings not used in the current study. Pilot data and feedback resulted in further refinement of the items, including the deletion of five items and addition of three new items. On the final 16-item SSCM, participants were asked to indicate the extent of their agreement using a 5-point Likert scale (from 1 = "Strongly disagree" to 5 = "Strongly agree") to items assessing sibling caregiving priorities.

Caregiving burden The Burden Assessment Scale (BAS) (Reinhard et al. 1994) assessed well siblings' perceptions of objective and subjective burden associated with caring for their sibling with mental illness. The BAS is a 19-item measure rated on a four-point scale with 0 indicating "not at all" and 3 indicating "a lot," with higher scores indicating higher levels of perceived caregiving burden. The BAS showed high internal consistency (α = .90).

Interaction guilt The Well Sibling Interaction Guilt Index (WSIGI) of the Well Sibling Guilt Questionnaire (Jewell 1999) assessed siblings' experiences of guilt related to their interactions with their sibling with mental illness. Items were rated on a five-point Likert scale from strongly agree to strongly disagree, with higher scores indicating higher levels of interaction guilt. The internal consistency for the WSIGI was .85.

Family satisfaction The Family Satisfaction Scale (FSS) (Carver and Jones 1992) is a 20-item self-report measure of satisfaction with one's family of origin. Items were rated on a 5-point Likert scale from "strongly disagree" (1) to "strongly agree" (5), with higher scores indicating higher levels of perceived family satisfaction. The FSS had high internal consistency (α = 95).

Current caregiving The Current Caregiving Scale (CCS) (Jewell and Stein 2002) assessed well siblings' perceptions of the amount of care they provided to their sibling with mental illness over the prior year. The 10-item CCS was adapted from existing caregiving measures (Horwitz 1993; Horwitz et al. 1992) to assess emotional support, assistance with basic needs, symptom management, family contact, and efforts to arrange for supportive services. Items were rated on a four-point scale (ranging from 1 = "none" to 4 = "frequently") with higher scores indicating higher levels of perceived caregiving. Internal consistency coefficient for the CSS was .87.

Intention to care The Intention to Care Scale was used to measure well sibling's intentions to provide caregiving in the future to their sibling with mental illness (ICS; Jewell and Stein 2002). The scale consists of five global items tapping intention to offer emotional support, arrange for supportive services, and provide assistance with basic needs, finances, and symptom management. Respondents were asked to indicate their agreement with each item, such as "I intend to help my sibling with emotional support sometime in the future," using a five-point Likert-type scale (from 1 = "Strongly agree" to 5 = "Strongly disagree"). In prior testing, the ICS demonstrated good internal reliability (α = .82) and was moderately correlated with the CCS (Jewell and Stein 2002). The internal consistency for the ICS in Study 1 was high (α = .82).

Data analyses

First, items on the SSCM were subjected to a principal components factor analysis to examine the measure's factor structure. Items that loaded onto factors were unit weighted and summed to compute subscale scores for the SSCM and the internal consistency of each factor was computed. Next, differences in the SSCM subscales were examined as a function of demographic factors that included participants' gender, age, support group affiliation, distance lived from sibling (i.e., living within one hour's drive from sibling vs. greater than one hour's drive away), self-reported primary caregiver status (yes/no), marital status (i.e., married/living with partner vs. unmarried), and parent status (i.e., no children vs. one or more children). Demographic differences were also tested in other main study measures. Finally, correlational analyses of the SSCM subscales and measures of caregiving, burden, family satisfaction, and guilt were conducted to assess the construct validity of the SSCM (Campbell and Fiske 1959).

Results

A three-component solution accounted for 55% of the total variance in the sample. Component factors were subjected to a Varimax rotation. Items and their factor loadings are presented in Table 2. Factor 1 accounted for 28.2% of the variance and the 6 items within the index comprised preferences for *balanced sibling-care priorities*, such as "I strive to find a balance between doing things for myself and

Table 2 Principal components factor analysis of self- and sibling-care measure (Study 1)

SSCM items (M = 3.19; SD = 1.09)	M	SD	SSCM subscales Balanced sibling-care priorities	Ambivalence	Self-care priorities
"I attend to both mine and my sibling's welfare"	3.09	1.09	.84		
"I strive to find balance between my own and my sibling's needs"	3.07	1.14	.76		
"I do the best I can to pay attention to both of our concerns"	3.65	1.03	.79		
"I take time to assist my sibling when needed"	3.52	1.09	.65		
"I place equal importance on my own and mysiblings' needs"	2.63	1.07	.57		
"it is my family duty to be involved with my ill sibling"	3.85	1.10	.47		
"I feel torn about how much to sacrifice"	3.02	1.16		.81	
"I have difficulty deciding when I should do things for my ill sibling"	2.68	1.14		.74	
"I feel caught in the middle about self/sibling focus"	2.53	1.08		.71	
"I have problems deciding between self/sibling care"	2.70	1.12		.66	
"I don't have time or energy to do things for my ill sibling"	2.67	1.07		.48	
"I focus on myself and own welfare/needs first"	3.42	1.01			.81
"at this point in life, I'm focusing on my own needs"	3.87	.97			.70
"I do not put ill sibling's needs before my own"	3.97	.92			.67
"I set limits or say 'no' when my sibling needs me"	3.37	1.16			.64
"I distance myself so I won't get too drained"	3.01	1.27			.55
Alpha reliability			α = .82	α = .80	α = .77

doing things for my ill sibling." Factor 2 accounted for 16.8% of the variance and the 5 items within the index encompassed *self-care priorities*, such as "I focus on myself and my own welfare/needs first and then worry about the needs of my ill sibling." The third factor accounted for 10.6% of the variance and the 5 items within this index incorporated sibling attitudes of *ambivalence* toward caregiving, such as "I feel 'torn' about how much I should personally sacrifice when it comes to meeting the needs of my ill sibling." Items that loaded onto balanced sibling-care, self-care, and ambivalence subscales were unit weighted and summed to compute subscale scores for the SSCM. The means and standard deviations of scores on the SSCM are reported in Table 3. SSCM subscales demonstrated acceptable internal consistency: balance Sibling-care, α = .82; ambivalence, α = .80; self-care priorities, α = .77.

Results indicated that scores on the ambivalence subscale of the SSCM showed significant differences as a function of gender, with women indicating higher levels of ambivalence ($M = 2.80$) than men ($M = 2.41$) in the sample ($t[1, 239] = -2.80$, $p < 01$). We found no other significant differences based on gender among the SSCM subscales. A Pearson product-moment correlation indicated that the balanced sibling-care priorities subscale was significantly correlated with participants' current age, $r(240) = .16$, $p < .05$, with older participants reporting higher levels of sibling-care priorities. Age was not significantly related to self-care or ambivalence subscale scores.

As expected, members of support groups like NAMI indicated higher levels of balanced sibling-care priorities ($M = 3.36$) than non-NAMI members ($M = 2.93$) in the sample ($t[1, 239] = -4.12$; $p < .01$). Support group members also indicated lower levels of self-care priorities than did non-support group members in the total sample ($t[1, 239] = 2.34$; $p < .05$; M = 3.43, support group members; $M = 3.66$ non-support group members). No significant differences were found in ambivalence toward sibling caregiving based on support group membership. Consistent with expectations, self-identified primary caregivers indicated higher levels of balanced sibling-care priorities ($M = 3.80$) than non-primary caregivers ($M = 3.02$) in the sample ($t[1, 239] = -6.49$; $p < .01$). Primary caregivers also indicated significantly lower levels of self-care priorities ($t[1, 239] = 5.58$; $p < .01$; M = 3.03, primary caregiver; $M = 3.66$ non-primary caregiver) and lower levels of ambivalence ($t[1, 239] = -2.31$; $p < .05$; M = 2.98, primary caregiver; $M = 2.67$ non-primary caregiver) than did non-primary caregivers in the total sample.

As hypothesized, higher self-care priorities were associated with living farther than an hour drive away from one's sibling ($t[1, 239] = 2.92$; $p < .01$; M = 3.36, within an hour's drive; $M = 3.64$, greater than an hour away), whereas well siblings living within an hour's drive of their sibling with mental illness reported higher levels of balanced sibling-care priorities ($M = 3.33$) than those living farther away ($t[1, 239] = -2.36$; $p < .05$; $M = 3.08$, greater than an

Table 3 Correlations between self- and sibling-care measure (SSCM) subscales and variables used to establish construct validity for the SSCM ($N = 242$) (Study 1)

Variables	M	SD	1	2	3	4	5	6	7	8
1. CCS	2.05	.68	–							
2. ICS	3.63	.91	**.32**	–						
3. SSCM-ambivalence	2.73	.86	**.32**	.05	–					
4. SSCM-self-care	3.52	.75	**−.54**	**−.29**	−.14*	–				
5. SSCM-sibling-care	3.20	.82	**.56**	**.32**	.10	**−.44**	–			
6. BAS	2.08	.56	**.34**	.13	**.51**	**−.19**	**.19**	–		
7. WSIGI	2.83	.91	.07	−.05	**.54**	.13*	**−.10**	**.49**	–	
8. FSS	3.45	.81	−.07	.10	**−.26**	**−.18**	.15*	**−.33**	**−.26**	–

CCS current caregiver scale, *ICS* intentions to care scale, *SSCM-ambivalence* ambivalence subscale of SSCM, *SSCM-self-care* self-care subscale of SSCM, *SSCM-sibling-care* balanced sibling-care subscale of SSCM, *BAS* burden assessment scale, *WSIGI* well sibling interaction guilt index, *FSS* family satisfaction scale

Correlations with * have a $p < .05$. Correlations in boldface have a $p < .01$

hour away). Contrary to hypotheses, well siblings who had one or more children reported higher levels of balanced sibling-care priorities than those with no children (Balance: $t[1, 239] = -.34$; $p < .05$, M = 3.17, no children, $M = 3.21$, one or more children), but no significant differences were found in reports of self-care priorities ($t[1, 239] = -.53$; $p > .05$, M = 3.50, no children, $M = 3.55$, one or more children) or ambivalence ($t[1, 239] = 1.82$; $p > .05$, M = 2.82, no children, $M = 2.61$, one or more children) based on well siblings' parent status. Unexpectedly, no significant differences were found on SSCM scores as a function of marital status (Balance: $t[1,239] = -.009$; $p > .05$, M = 3.19, married, $M = 3.19$, unmarried; Self-Care: $t[1, 239] = -1.56$; $p > .05$, M = 3.59, married, $M = 3.44$, unmarried; Ambivalence: $t[1, 238] = .54$; $p > .05$, M = 2.70, married, $M = 2.76$, unmarried).

Regarding demographic differences in main study measures, all measures except the FSS and the ICS significantly differed based on gender, including the CCS ($t[1, 240] = -2.49$; $p < .05$; M = 1.82, male, $M = 2.10$, female), BAS $t[1,240] = -5.70$; $p < .01$; M = 1.66, male, $M = 2.17$, female), and WSIGI ($t[1, 239] = -4.17$; $p < .01$; M = 2.33, male, $M = 2.94$ female), with females reporting higher levels of current caregiving, caregiver burden, and interaction guilt. However, it should be noted that there were more females ($N = 198$) than males ($N = 44$) in the current sample. Only CCS was statistically related to age, $r(241) = .20$, $p < .01$, with older participants reporting higher levels of current caregiving. Results also showed significant differences for the CCS, ICS, and BAS as a function of support group membership, with support group members indicated higher levels of current caregiving ($M = 2.18$) than non-support group members ($M = 1.85$) ($t[1, 240] = -3.88$; $p < .01$; M = 2.18, support group members; $M = 1.85$, non-members) and higher intentions to care $t[1, 240] = -2.12$; $p < .05$; M = 3.72, support group members; $M = 3.48$, non-support group members) than non-members. Support group members also indicated higher levels of burden than non-support group members ($t[1, 240] = -3.94$; $p < .01$; M = 2.18, support group members; $M = 1.90$, non-members).

Table 3 displays correlation coefficients between scores on subscales of the SSCM and scores on measures of current caregiving (CCS), intentions to care (ICS), caregiving burden (BAS), family satisfaction (FSS), and well sibling interaction guilt (WSIGI). As expected, the self-care subscale score of the SSCM was significantly negatively correlated with reported current caregiving ($r = -.54$; $p < .01$), intentions to care ($r = -.29$; $p < .01$), caregiver burden ($r = -.19$; $p < .01$), and family satisfaction ($r = -.18$; $p < .01$). Self-care scores were significantly positively correlated with reported interaction guilt ($r = .13$; $p < .05$).

As expected, balanced sibling-care scores were significantly positively correlated with scores of current caregiving ($r = 56$: $p < .001$), intention to care ($r = .32$; $p < .001$), reported caregiver burden ($r = .19$; $p < .01$), and family satisfaction ($r = .15$; $p < .05$). Additionally, as hypothesized, balanced sibling-care scores were not significantly associated with sibling interaction guilt.

As hypothesized, ambivalence scores were significantly positively correlated with current caregiving scores ($r = .32$; $p < .01$), caregiver burden ($r = .51$; $p < .01$), and interaction guilt ($r = .54$; $p < .01$). Ambivalence scores were negatively correlated with family satisfaction ($r = -.26$; $p < .01$) and not significantly associated with intentions to care.

Intercorrelations among SSCM subscales were also in expected directions. The self-care and balanced sibling-care subscales showed a highly significant negative correlation with on another ($r = -.44$, $p < .01$), whereas the negative correlation between the self-care and ambivalence subscales was significant but less strong ($r = -.14$, $p < .05$). Balanced sibling-care and ambivalence subscales were not significantly correlated with on another ($r = .10$, $p > .05$).

Study 2

Method

Participants

A total of 103 eligible participants (81 women and 22 men) were recruited for Study 2 (see Table 1 for a summary of demographic data). A majority of study participants were Caucasian (90.3%) and their average age was 38.9 years (SD = 13.8). Approximately one-half (52%) of participants were married or living with a partner, and more than half (51%) of the sample reported having no children. The overall sample was highly educated, largely reporting that they had either completed "some college" (30%), "a 4 year college degree" (32%), or an "advanced degree (graduate training)" (32%). A majority of participants identified themselves as being Christian or Catholic (59%) or as having no religious affiliation (26%).

When asked about mental health, 43% of respondents indicated they had been diagnosed with a personal mental health problem, such as depression (53%). Sixty-four well siblings (62%) reported no affiliation with family support and advocacy groups like NAMI. Only one-fifth (18%) of the current sample reported that they act as a primary caregiver for their siblings, but among siblings who were not self-identified as primary caregivers, 60% reported that a parent currently held this role. Over half (52%) of participants reported being "moderately involved" to "very involved" in the life of their sibling with mental illness, and two-thirds (62%) reported being "moderately" to "very" close to their sibling.

Most participants' indicated that their sibling was male (64%), single (76%), with no children (77%), and in their late 30 s ($M = 38.4$, SD = 13). Many participants (70%) indicated that their siblings' education level included at least "some college." Two-thirds (64%) of participants reported that their sibling with mental illness had been diagnosed with schizophrenia or schizoaffective disorder, with the majority (68%) of the overall sample having been diagnosed between 5–10 years (26%), 10–20 years (19%), or more than 20 years ago (23%). Seventy-six percent of participants indicated their sibling was "unemployed" or "disabled," while most were either living with a family member (37%) or living independently with no formal supervision (34%). Many participants (67%) indicated that their sibling had regular contact with a mental health provider.

Procedure

After receiving approval for the research from the Institutional Review Board of a Midwestern university where the research was conducted, we invited individuals to participate through study announcements placed on websites related to mental illness and in online newsletters distributed primarily by NAMI. Participants were also recruited through telephone and email contacts with well sibling support group facilitators and leaders of state and local chapters of NAMI. We made 287 calls and distributed 167 emails to sibling support group facilitators, leaders of state and local chapters of the NAMI, and individual siblings who expressed interest in the study. A total of 103 questionnaires were valid for inclusion in the current study, with 3 participants' responses considered invalid because their ill sibling was no longer living.

Measures

Sibling support and advocacy group affiliation Support group affiliation was scored based on whether participants' reported no involvement in sibling support or advocacy groups like NAMI ($n = 64$) or involvement in *a* family support group or another kind of advocacy group like NAMI ($n = 34$).

Current caregiving scale The 10-item CCS used in Study 1 was also used in Study 2. Cronbach's alpha for the CCS in Study 2 was .90.

Intentions to care The ICS was also used in Study 2 (Jewell and Stein 2002). The internal consistency for the ICS in Study 2 was high (α = .89).

Self- and sibling-care attitudes The extent to which well siblings prioritize their personal needs over the needs of their sibling with mental illness was measured using the SSCM psychometrically evaluated in Study 1. Internal consistency coefficients for the SSCM subscales in Study 2 were α = .80 (Ambivalence), α = .82 (Balanced Sibling-Care Priorities), and α = .77 (Self-Care Priorities).

Personal loss The personal loss from mental illness scale (PLMI; Stein et al. 2005) assesses the personal, relationship, and psychosocial losses reflected in having to confront the challenges of mental illness. The PLMI taps the following areas of personal loss as a result of mental illness: loss of social roles and routines, loss of former relationships, loss of former self, and loss of a sense of future. The personal loss from mental illness-sibling version (PLMI-S) consisted of 20-items adapted for siblings, such as "Since my sibling's illness, I doubt that I will have the same kind of future as other people my age." which participants' rated on 5-point Likert scale (from 1 = "strongly disagree" to 5 = "strongly agree"). An overall loss score was used in the present study. The internal consistency for the PLMI-S in Study 2 was .86.

Stress-related personal growth Park et al.'s (1996) 50-item stress-related growth scale (SRGS) was developed into short-form comprised of the 15 highest-loading items (Cohen et al. 1998). The SRGS short-form was used to assess ways that siblings believe they have experienced personal growth due to having a sibling with a mental illness. This measure includes items such as "I learned to find more meaning in life" and "I learned to reach out and help others" as a result of having a sibling with a mental illness. Participants responded on a 3-point Likert scale ranging from 0 = "Not at all" to 2 = "A great deal." The SRGS has demonstrated good internal reliability (α = .94) and test-retest reliability (.81) (Park et al. 1996). In Study 2, Cronbach's alpha for the SRGS in the present study was also high (α = .94).

Data analyses

Similar to Study 1, in Study 2 we tested differences in the SSCM subscales as a function of participants' gender, age, support group affiliation, distance lived from sibling, self-reported primary caregiver status, marital status, and parent status. We also tested for demographic differences in other measures included in Study 2. We computed Pearson bivariate correlations among all measures included in Study 2, including personal loss, stress-related growth, current caregiving and intentions to care, and self- and sibling-care measures. Finally, we conducted a series of hierarchical multiple regression analyses to examine whether self- and sibling-care attitudes contributed to the prediction of well siblings' reports of personal loss and stress-related growth, after accounting for participant demographic and support group affiliation characteristics and perceptions of well siblings' caregiving behaviors. In each regression analysis, Step 1 consisted of gender, age, and support group affiliation; Step 2 consisted of participants' perceptions of current caregiving and intentions to provide care; and Step 3 consisted of participants' average scores on subscales of the self- and sibling-care measure (balanced sibling-care priorities, self-care priorities, ambivalence).

Results

Findings indicated that there were no significant differences in SSCM subscale scores based on well siblings' gender, marital status, distance lived from sibling, or parent status in Study 2. Age was significantly negatively correlated with self-care priorities ($r = -.32$, $p < .01$), such that younger well siblings endorsed greater preference toward self-care than sibling caregiving. Well siblings who were members of a support or advocacy group like NAMI showed significantly higher levels of balanced sibling-care priorities ($t[1, 101] = -2.46$; $p < .05$; $M = 3.68$, support group member, $M = 3.28$, no affiliation) than siblings who were not involved in any support groups. Well siblings who identified as primary caregivers reported significantly lower levels of self-care priorities ($t[1, 100] = -3.74$; $p < .01$; $M = 2.76$, primary caregivers, $M = 3.47$, non-primary caregivers), but in contrast to findings from Study 1, primary caregiver status was significantly associated with higher levels of ambivalence (not balanced sibling-care priorities) toward caregiving ($t[1, 100] = 2.84$; $p < .01$; $M = 3.70$, primary caregivers, $M = 3.00$, non-primary caregivers).

Table 4 Zero-order correlation matrix for Study 2 ($N = 103$)

Variables	M	SD	1	2	3	4	5	6	7
1. CCS	2.16	.80	–						
2. ICS	3.68	1.06	**.51**	–					
3. SSCM-Ambivalence	3.13	.99	**.49**	**.46**	–				
4. SSCM-Self-Care	3.34	.79	−**.57**	−**.43**	−**.29**	–			
5. SSCM-Sibling-Care	3.43	.82	**.47**	**.43**	**.34**	−.54	–		
6. PLMI-S	2.85	.69	**.37**	.17	**.54**	−.18	.09	–	
7. SRGS	1.15	.56	.14	.08	.02	−.10	**.27**	.04	–

CCS current caregiver scale, *ICS* intentions to care scale, *SSCM-ambivalence* ambivalence subscale of SSCM, *SSCM-self-care* self-care subscale of SSCM, *SSCM-sibling-care* balanced sibling-care subscale of SSCM, *PLMI-S* personal loss due to mental illness (Sibling Version), *SRGS* stress-related growth scale

Correlations with * have a $p < .05$. Correlations in boldface have a $p < .01$

Age was significantly positively correlated with CCS ($r = .27$, $p < .01$), such that older well siblings endorsed higher levels of current caregiving. Well siblings who were members of a support or advocacy group like NAMI generally reported significantly higher levels of current caregiving ($t[1, 101] = -2.94$; $p < .01$; $M = 2.45$, support group member, $M = 1.99$, no affiliation) and levels of stress-related growth ($t[1, 101] = -3.59$; $p < .01$; $M = 1.39$, support group member, $M = 1.00$, no affiliation) than siblings who were not involved in any support groups. Additionally, participants in Study 2 were asked about their mental health status (i.e., having a mental health diagnosis or not), however, no significant differences were found in any Study 2 measure on the basis of mental health status.

Table 4 presents correlations among all measures included in Study 2. Similar to Study 1, subscales of the self- and sibling-care measure were moderately correlated with one another ($rs = -.54$, $-.29$, and $.34$, $p < .01$). Balanced sibling-care priorities and ambivalent attitudes toward caregiving were moderately positively correlated with current caregiving and intentions toward care (balanced sibling-care: $rs = .47$ to $.43$, $p < .01$; ambivalence: $rs = .49$ to $.46$,

Table 5 Hierarchical regressions of personal loss and stress-related growth (Study 2)

			B					
Criterion variable	Predictor variables	R^2 Chg	Step 1	Step 2	Step 3	R^2	Adj R^2	R
Personal loss	1. Gender	.06	.21*	.22*	.18*	.06	.03	.65**
	Age		.01	−.07	−.05			
	Support group affiliation		.14	.04	.02*			
	2. Intentions to care	.14**		.04	−.12	.20	.16	
	Current caregiving			.38**	.19			
	3. SSCM-sibling-care	.22**			−.08	.42	.34	
	SSCM-ambivalence				.56**			
	SSCM-self-care				−.08			
Stress-related growth	1. Gender	.10*	.14	.14	.17	.10	.07	.42*
	Age		.05	.05	.06			
	Support group affiliation		.26*	.26*	.23*			
	2. Intentions to care	.00		.02	−.02	.10	.05	
	Current caregiving			−.01	−.07			
	3. SSCM-sibling-care	.08*			.35**	.18	.10	
	SSCM-ambivalence				−.05			
	SSCM-self-care				−.09			

SSCM-Ambivalence ambivalence subscale of SSCM, *SSCM-Self-Care* self-care subscale of SSCM, *SSCM-Sibling-Care* balanced sibling-care subscale of SSCM

$^{*}p < .05$; $^{**}p < .01$

$p < .01$). Self-care priorities were moderately negatively correlated with current caregiving and intentions to care (Self-Care: $rs = -.57$ to $-.43$, respectively, $p < .01$). Additionally, current caregiving and intentions to care scores were moderately positively correlated with each other ($r = .51$, $p < .01$). Well siblings' reported personal loss was positively correlated with ambivalent attitudes toward caregiving ($r = .54$, $p < .01$) and current caregiving ($r = .37$, $p < .01$), whereas stress-related growth was positively correlated with balanced sibling-care priorities ($r = .27$, $p < .01$).

Results of hierarchical regression analysis for Study 2 are presented in Table 5. When using personal loss as the criterion measure, the overall regression model was significant, $F(8, 98) = 2.45$, $p < .001$. In Step 1, well sibling demographic characteristics, specifically gender ($\beta = .21$, $p < .05$) but not support group affiliation or age, significantly predicted perceptions of personal loss. In Step 2, the addition of ratings of current caregiving ($\beta = .38$, $p < .01$), but not intentions to care, significantly predicted personal loss. In Step 3, the addition of reports of ambivalence toward self- and sibling-care ($\beta = .56$, $p < .001$), but not balanced sibling-care priorities or self-care priorities, accounted for an additional 22% of the variance in reported personal loss. Results suggest that, after accounting for demographic and caregiving characteristics, ambivalence toward the prioritization of self and sibling caregiving contributed to well siblings' perceptions of personal loss.

When using stress related growth as the criterion measure, the overall regression model was significant, $F(8, 98) = 2.42$, $p < .05$. In Step 1, well siblings' support group affiliation ($\beta = .26$, $p < .05$), but not age or gender, accounted for 10% of the variance in reports of stress-related growth. Well siblings who were engaged in a number of support groups were more likely to report feeling greater stress-related growth. In Step 2, perceptions of current caregiving and intentions to care did not make a significant contribution to the prediction of stress-related growth. In Step 3, balanced sibling-care priorities ($\beta = .35$, $p < .01$), but not self-care priorities or ambivalence toward caregiving, accounted for an additional 8% of the variance in stress-related growth. Results suggest that, after accounting for demographic and caregiving characteristics, well siblings who took a balanced approach toward caring for their siblings with mental illness were more likely to report experiencing growth from the stress of their experience.

Discussion

The present research incorporated two cross-sectional studies to examine the role of self- and sibling-care attitudes among adults who have a sibling with a serious mental illness. Using a sample of 242 well siblings, Study 1 developed and evaluated the self- and sibling-care measure

(SSCM), a self-report measure designed to assess the caregiving preferences of well siblings of individuals with serious mental illness. We found the SSCM to be psychometrically sound with a multi-factor structure that differentiated three subscales: ambivalence, balanced sibling-care priorities, and self-care priorities. Using a separate sample of 103 adults, Study 2 examined the contribution of the self- and sibling-care measure to the prediction of well-siblings' perceptions of personal loss and stress-related growth related to having a sibling with serious mental illness. Findings indicated that self- and sibling-care priorities differentially accounted for well siblings' perceptions of personal loss and stress-related growth beyond demographic factors, support group affiliation, and self-reported caregiving behaviors and intentions.

Study 1 provided support for the construct validity of the SSCM. Overall, the moderate magnitude of correlations between measures suggested that the subscales that comprise the SSCM are statistically and theoretically distinct from caregiving behaviors and intentions, caregiver burden, family satisfaction, and sibling interaction guilt. The discriminant validity of the ambivalence subscale of SSCM was also arguably supported given that it was unrelated to reported intentions to care in Study 1, suggesting that well siblings who endorsed ambivalence in this sample did not have definitive expectations about their role in future sibling caregiving. Present findings also suggest that relationships between SSCM scores and a variety of demographic and situational characteristics were largely in expected directions, providing further support for the construct validity of the SSCM. Subscale scores of the SSCM in Study 1 differed in predictable ways as a function of participants' reports of support group membership, primary caregiver status, and geographical distance from their sibling with mental illness. Contrary to our hypotheses and to prior research (Greenberg et al. 1999), well siblings in Study 1 who had children endorsed greater balanced sibling-care priorities, suggesting that well siblings did not see having children as a barrier to providing care to their sibling with mental illness. A consistent lack of significant differences in self- and sibling-care scores based on marital status may have been a function of sample characteristics.

Study 1 findings also suggest that well siblings' caregiving attitudes have noteworthy implications for families of adults with serious mental illness. Well siblings who endorsed greater self-care priorities reported lower levels of current caregiving, intentions to care, caregiver burden, and family satisfaction, but greater levels of sibling interaction-related guilt. That is, well siblings who prioritized their own needs indeed generally reported less participation in caregiving, and correspondingly, did not endorse the burdens typically associated with caregiving or as much satisfaction from family relationships. They did, however, report greater guilt in their interactions with their siblings with mental illness. In contrast, siblings who endorsed a balanced approach toward caregiving were not only more likely to report higher levels of current sibling caregiving, intentions to care, and caregiver burden, but also appeared to derive greater satisfaction from their role in the family. These findings are consistent with previous research on parents of adults with mental illness, which showed that parents who provided greater daily assistance to their adult children with mental illness reported both greater subjective burden and greater personal gains than those who were less involved in caregiving (Aschbrenner et al. 2014; Chen and Greenberg 2004). Our findings suggest that well siblings who take a balanced approach toward caregiving are also more likely to experience an array of gains and losses from their caregiving interactions with their siblings with serious mental illness.

Adults who reported ambivalent caregiving attitudes among well siblings also reported higher levels of current caregiving and higher levels of perceived burden. Although research on ambivalence in family relationships has primarily been conducted on parent–child and other intergenerational relationships (Birditt et al. 2010; Fingerman and Hay 2004), past studies suggest that intergenerational ambivalence is associated with poorer family relationships in early life, greater tension in sibling relationships, and poorer psychological adjustment and quality of life (Fingerman et al. 2008; Lowenstein 2007; Waite-Jones and Madill 2008; Willson et al. 2003). Our findings support the notion that ambivalence about providing care is associated with unfavorable family dynamics, including greater interaction guilt among siblings and lower levels of satisfaction with their family relationships.

In Study 2 results, self- and sibling-care attitudes accounted for significant variance in the prediction of siblings' scores on personal loss and stress-related growth above and beyond demographic factors, support group affiliation, and self-reported caregiving behaviors and intentions. Specifically, well siblings' endorsement of ambivalence toward caregiving was predictive of perceived personal loss related to having a sibling with mental illness above and beyond the effects of gender and reported caregiving engagement. In contrast, endorsement of balanced sibling-care priorities was predictive of stress-related growth after taking into account the contribution of support group involvement and the potential role of caregiving behavior. Self-care priorities were not significantly predictive of either growth or loss.

Present findings suggest that well siblings reports of balancing their own needs with the caregiving needs of their sibling derived a sense of personal growth from their caregiving role, regardless of demographic factors and perceived caregiving intentions and behaviors. In contrast, ambivalence toward sibling caregiving appeared to reflect an inability to successfully negotiate self and sibling needs, which heightened siblings' perceptions of personal loss due to having a sibling with mental illness. These findings contrast those of Luscher (2002) and Lashewicz et al. (2012), who found that feelings of ambivalence toward caregiving propelled siblings to resolve this tension by remaining involved in caregiving tasks while also setting limits to preserve aspects of their own well-being.

In contrast to balanced or ambivalent attitudes toward caregiving, siblings' self-care priorities reflect a stance of intentional distancing from potential caregiving obligations, as evidenced by findings showing that self-care priorities were associated with lower current caregiving and intentions to care. Given existing literature has emphasized the role of self-care in promoting wellness and lessening burden (Acton 2002), well siblings who chose to prioritize self-care over caregiving for their sibling with mental illness might be expected to endorse higher levels of growth. However, siblings' self-care priorities did not make a significant contribution to the prediction of either stress-related growth or personal loss. Well siblings of adults with serious mental illness often contend with impediments (e.g., their own work or financial responsibilities) that may lower their ability, intentions, or willingness to provide care (Abraham and Stein 2013; Hatfield and Lefley 2005). Additionally, self-care priorities in sibling caregiving likely do not involve the respite or stress relief typically associated with engagement in traditional notions of self-care.

The cross-sectional nature of the present research precludes definitive statements about the causality among variables. The validation of the SSCM scales is limited by the exclusive use of self-report data in both samples. Moreover, the limited sample size of Study 2 prevented further exploration of the factor structure of the SSCM through procedures such as confirmatory factor analysis (Kline 2005; Brown 2006). Future research is needed to further assess the psychometric properties of the SSCM and examine its behavioral correlates. Although we did consider differences in participants' responses based on support group affiliation, the generalizability of our findings is limited by sample recruitment methods. Prior research suggests that siblings who are affiliated with support groups can differ in important ways from siblings who do not joining family support groups (Rowitz 1993).

Findings from these two independently conducted studies shed light on the caregiving attitudes and preferences of well siblings of individuals with serious mental illness. Studies are needed that evaluate the role of sibling caregiving attitudes on other indices of personal and family functioning, including psychological well-being and other indices of family satisfaction. Future research is also needed to replicate and extend these findings and examine factors that influence sibling caregiving attitudes at different phases of the life course.

Author Contributions J.E.L. designed and executed Study 2, completed data analysis for Study 2 and additional data analysis for Study 1, wrote the manuscript integrating both Study 1 and 2, and edited the final manuscript. T.C.J. designed and executed Study 1 and completed data analysis for Study 1. C.H.S. advised J.E.L. and T.C.J. in the development of Study 1 and 2, assisted in the analysis and writing of the manuscript, and edited the final manuscript.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interests.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional review board at Bowling Green State University and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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