



HHS Public Access

Author manuscript

Psychiatr Serv. Author manuscript; available in PMC 2015 July 27.

Published in final edited form as:

Psychiatr Serv. 2015 May 1; 66(5): 527–535. doi:10.1176/appi.ps.201400135.

Impact of Patients' Psychiatric Hospitalization on Caregivers: A Systematic Review

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Abstract

Objective—The purpose of this article was to systematically review literature on the impact of patients' psychiatric hospitalizations on caregivers. Implications for practice and research are presented.

Methods—A systematic search of Web of Knowledge, PsychInfo, and Medline (PubMed) was conducted for peer-reviewed articles published before August 31, 2013. Qualitative, quantitative, and mixed method studies were included if they focused on caregiver outcomes and contained data collected directly from caregivers of patients who had been psychiatrically hospitalized.

Results—Twenty-nine articles met the inclusion criteria. Caregivers are heterogeneous in their reaction to the psychiatric hospitalization; however, many report distress. Caregivers also often report that they experience stigma, disruptions in daily life, worse physical health, economic strain, and changes in relationships following hospitalization. Negative reactions to the hospitalization may decrease over time, but can remain elevated when compared to the general population. Nonetheless, many caregivers also experience positive changes as a result of the hospitalization. The reaction of caregivers may be influenced by the severity of the patient's psychiatric problems as well as the caregiver's demographics and style of coping.

Conclusions—Caregivers experience a range of reactions to the psychiatric hospitalizations and providing caregivers with psychoeducation on their possible reaction as well as techniques to assist them may improve clinical outcomes for patients. Future research is needed to understand the heterogeneity in caregiver's reactions to the patient's psychiatric hospitalization.

The trend toward brief psychiatric hospitalizations may place increased demands on caregivers both during and after patient psychiatric hospitalization. Short inpatient stays may

increase caregivers' need to adjust and resolve seemingly insurmountable circumstances with little-to-no external support, both during and after discharge. Furthermore, caregivers may need to support the patient after discharge because symptoms persist.

This article provides systematic review this literature and addresses three questions: What are the effects of psychiatric hospitalization on caregivers of patients? Do the effects on caregivers change over time? and What factors influence the impact of the psychiatric hospitalization on caregivers? This review extends previous reviews (1, 2) by focusing on multiple ways psychiatric hospitalizations can affect caregivers of patients with a variety of psychiatric problems (not just a particular diagnosis).

Methods

This review was informed by three database searches: Web of Knowledge, PsychInfo, and Medline (PubMed). Drawing on Angold and colleagues' work (3), our review examined multiple ways caregivers could be negatively (well-being, stigma, relationship changes, daily life, economic strain, and physical health) and positively impacted by the hospitalization. Search terms included: psychiatric or mental health AND inpatient or admission or hospital AND family members or caregiver or parent. Abstracts published before August 31, 2013 were reviewed; relevant articles and their reference lists were examined against inclusion criteria. Studies were included that focused on caregiver outcomes, data collected from caregivers of patients (of any age) who were psychiatrically hospitalized for any reason, and were peer-reviewed and published in English. Studies were excluded that recruited caregivers from both inpatient and out-patient settings (4, 5) or included data collected prior to 1980 (6–9). All articles (n=111) were independently reviewed and reviewed by another team member. Discrepancies to whether a study met inclusion criteria were discussed (n=20) and consensus was obtained. Twenty-nine articles met inclusion criteria.

Results

Caregiver and patient characteristics are presented in Table 1. Thirteen studies focused on caregivers of adults, eight on caregivers of youth, two of both, and six did not specify. Seven studies indicated possible previous hospitalizations and 24 included patients' age. Time between hospitalization and follow-up assessments was not provided in six studies, but ranged from data collected during hospitalization (baseline) to approximately four years post-hospitalization. Table 2 summarizes methods used and areas of impact on caregivers.

Effects of psychiatric hospitalization on caregivers of patients

Psychological Well-Being—Twenty-eight studies examined caregiver psychological well-being. Qualitative interviews with caregivers of adults revealed caregivers felt isolated and confused when dealing with mental health professionals (10). Further, caregivers of adults hospitalized for the first time reported experiencing disbelief and shame (11). In one study, 32 caregivers of adult patients with bipolar affective disorder reported feeling helpless, hopeless, and confused about the patient's behavior. In a study of 37 sibling-

caregivers of adults with schizophrenia, siblings reported experiencing psychological distress due to the illness and patients' management of the illness (11).

Using data from caregivers of youth, quantitative studies comparing caregivers of hospitalized individuals to caregivers of individuals not hospitalized (12–15) found the former group experienced more distress than the latter. For example, caregivers reported experiencing more distress, as measured by the general severity index of the SCL-90, three days after their adolescent was admitted to the hospital than caregivers of a non-clinical sample (16). In addition, fathers of suicidal adolescents with mood disorders reported more somatic symptoms, hostility, anxiety, and depression than either fathers of non-hospitalized adolescents or fathers of adolescents hospitalized for other reasons, even after controlling for severity of adolescent depression (13). Mothers of youth hospitalized for mood disorders, regardless of whether they had a history of suicidal behaviors, reported more somatic symptoms, obsessive/compulsive symptoms, anxiety, and hostility than mothers of non-hospitalized adolescents; these differences were not significantly different after controlling for severity of adolescent depression.

Using quantitative and qualitative methods, one study assessed parents' well-being before their adolescent attempted suicide, after first learning of the attempt, and the day after the attempt (17). Across time points, mothers reported increased sadness, anxiety, hostility, and caring. Fathers reported sadness and caring after the suicide attempt relative to before the attempt, but reported less anxiety than mothers.

Findings regarding caregiver mental health are not uniform across studies. For example, in a study of 63 caregivers of adults with first-onset of schizophrenia, fewer than 10% of female caregivers experienced significant distress as reflected by global severity scores on the SCL-90 (18). Similarly, caregivers (N = 32) of geriatric patients did not report elevated scores on the Brief Symptom Inventory (19).

Stigma—Caregivers may experience stigma associated with patients' psychiatric hospitalization. Stigma may be reflected in caregivers' negative self-valuation, feelings of shame or embarrassment, or their perceptions of being viewed or treated differently by others, presumably because of the caretaking role and association with the patient (20). Caregivers may also be self-devaluing, or concerned about others' perceptions about causes of the illness such as genetics or patients' upbringing.

Six studies addressed caregivers' experiences of stigma (20–25). Caregivers of 16- to 24-year-olds with non-affective psychotic disorder reported feeling ashamed, describing schizophrenia as “the ‘s’ word” and “a dirty word” (23). Caregivers of 25 adults in an extended care hospital reported “struggling” with the patients' mental illness, wariness regarding their family's and community's reaction to the illness, and selective acknowledgement of the illness among relatives (24). Similarly, caregivers of young adults reported not sharing the illness and hospitalization with friends, co-workers, and in one instance, a hospitalized person's siblings (21). Caregivers also reported exacerbated feelings of isolation experienced during the hospitalization (21). In a cross-sectional quantitative study, the extent to which 156 caregivers of patients between the ages of 16 and 26 and

hospitalized for psychosis and who had disclosed the mental illness to others were assessed 6 month post-hospitalization (20). Forty percent of caregivers either concealed the hospitalization from everyone or told only a few people.

Daily Life—Six studies examined changes in caregivers' daily life. Five studies focused on caregivers of adults (19, 22, 26–28) and one study did not report the patients' age (29). In assessments conducted at least six months post-hospitalization, almost 30% of 125 caregivers reported disruption in their everyday activities (27). Caregivers (N=162) of patients hospitalized for violence or suicide attempts reported similar findings using a semi-structured, reliable, Swedish instrument (26). Three weeks after discharge, 28% of caregivers reported lost leisure time, 33% not being able to have company, and 16% of caregivers quit working (26). Twelve percent of caregivers (N = 41) of adults with bipolar disorder reported limitations in their work, and among caregivers that worked outside of their home, 76% reporting reduced number of hours worked or taking time off (22). In contrast to these findings, 32 caregivers of geriatric patients reported life changes that were not significantly different from those of a normative sample of college students on the Life Experience Survey(19). Caregivers commonly reported changes in sleeping and eating patterns.

Economic Strain—Five studies examined economic strain among caregivers (6, 7, 22, 24, 27, 30, 31). In a sample of 125 caregivers of adults, 38% reported financial strain six months after the patient was discharged (27). Similarly, of the 41 caregivers of adults with bipolar disorder, interviewed 2 years after the hospitalization, 27% reported a reduction in their income (22). Similar findings were reported by other researchers (6, 7, 24) using assessments conducted during the hospital. Furthermore, caregivers of youth reported a link between economic strain and coping difficulties (30, 31). Economic strain may result because of cost of treatment and travel to the hospital or treatment site (24).

Physical Health—Two studies examined the impact of the psychiatric hospitalization of adult patients on caregivers' physical health (29, 32). Caregivers of individuals with depression or bipolar disorder reported more bodily pain and less energy than individuals in the community, matched by age (32, 33). In the second study (age of patients unspecified), 16% of caregivers of patients with schizophrenia reported the illness impacted their or a family member's physical health (29).

Relationships—Six studies examined caregiver-adult patient relationships (8, 11, 12, 22, 24, 29–31) and another examined changes in caregivers' relationships with others following hospitalization (24). Using data collected two years after the patient was discharged, 90% of caregivers felt their relationship with the patient was distant (22). Moreover, 44% of the caregivers (especially partners) reported experiencing violence or feared experiencing violence from the patient. Partners also reported sexual relationship issues which sometimes persisted even after the patient recovered. In a sample of 64 caregivers of patients with schizophrenia, 73% reported their relationship with the patient had partly worsened since the hospitalization, which occurred about four years prior to the assessment (29). In contrast to changes in relationships with the patient, caregivers in one study, in general, did not report

changes in relationships with others following hospitalization (24). Caregivers of youth reported similar findings – no effect (15) or negative effect (30, 31).

Positive Impact—Four studies reported the hospitalization had a positive impact on the caregivers (11, 22, 32, 33). Caregivers reported caregiving was rewarding (32) or improved relationships when the patient was doing better (22). One caregiver reported, “He’s more open with me now than he used to be. And I’m more nurturing than I used to be – I take more care of him and listen more” (22). Similarly, in the narratives of sibling-caregivers of patients with schizophrenia, siblings reported a “deeper bond with the sibling,” a “more intense bond among family members,” and other positive outcomes (11). Further, siblings reported that their experience with the patient often shaped their choice to work in the social sector.

Effects on caregivers over time

Six studies focused on the effects of psychiatric hospitalization over time on caregivers (33–38). In a series of studies, Moller-Leimkuhler and colleagues (34–37) examined the impact on caregivers of individuals (age unspecified) with schizophrenia or depression from Munich. Using data collected three weeks post-discharge (baseline), they found 71% of caregivers reported changes in their daily routines and 64% reported restrictions in leisure activities because of problems related to patients’ behavior. Caregivers also reported higher levels of distress, as measured by the SCL-90, than normative samples (34). These negative effects continued one year post-discharge, although the level of impairment or interference was often less severe than reported at baseline (35). Two years post-discharge, caregivers reported few changes in their daily lives or being bothered by the patient; however, compared to normative scores, their scores remained elevated (37). In addition, caregivers did not report a significant improvement in their well-being, as measured on the SCL-90, from year-1 to year-2.

Another study examined whether caregivers of individuals with depression (n=12) were impacted differently than caregivers of adults with bipolar disorder (n=10) in the year following hospitalization (33). Due to small sample size, the authors reported trend level data toward a decreased strain among caregivers of patients with bipolar disorder and not change with caregivers of patients with depression.

A study by Snell and colleagues examined changes in depression and anxiety among caregivers of youth with various diagnoses (38). From one week to three weeks post-hospitalization, 35 caregivers rated their distress using a Likert scale (ranging from 1 to 7, with 7 indicating more anxiety or depression); their ratings decreased significantly from week-1 to week-3.

Factors influencing the impact on caregivers

Fifteen studies examined factors associated with how caregivers are impacted by a patient’s psychiatric hospitalization (13, 18–20, 25–27, 30–32, 35–37, 39, 40), particularly reason for hospitalization and/or diagnosis of the patient. The majority of these studies focused on caregivers of adult patients. In several studies, compared to caregivers of patients

hospitalized for other reasons, caregivers of patients hospitalized for a suicide attempt reported more issues with negative well-being (i.e., mental health and worry) (26, 39). Compared to caregivers of patients with depression, caregivers of patients with bipolar disorder reported more changes in their life style, worse family functioning, and not feeling as much reward for providing care one year after discharge (33).

Caregiver demographics (e.g., gender, race/ethnicity, and socioeconomic status) also were identified as potential factors associated with the impact of hospitalization on caregivers. Gender differences were not associated with caregiver reports of stigma (27) or psychological distress (37) among caregivers of adults. On the other hand, results of one study indicated mothers of youth may experience more changes in their lives than fathers (13). With regards to race and ethnic differences, Black caregivers, in one study, reported less impact on their roles/responsibilities than White and Hispanic caregivers (25). The role of caregiver socioeconomic status is unclear. One study noted caregivers with high socioeconomic status reported more stigma than individuals with lower socioeconomic status (20), whereas this difference was not noted in another study (27).

Four studies examined caregiver coping (18, 30, 31, 40). Caregivers of adults reported using avoidance coping-strategies, which was linked more negative changes in their daily life (18). Caregivers of youth reported using emotional and instrumental or hands-on support (31) and access to respite-care was associated with less stress (40). In spite of these resources, caregivers of youth reported needing more support (30, 31).

Factors that change over time may also explain how caregivers are impacted. One study (age of patients unspecified) provided the following reasons for changes over time: “[expressed emotion], patients’ residual symptoms, patients’ global functioning, neuroticism, emotion-focused coping, problem-focused coping, self-efficacy, general negative stress response, perceived social support, additional life stressors, extraversion, sociability, openness, conscientiousness” (37). Caregiver personality traits were associated with caregiver well-being, with higher scores of neuroticism, as measured by the NEO Five-Factor Inventory, being associated with poorer well-being (36).

Discussion

This systematic review summarizes 29 articles and highlights the impact of a patients’ psychiatric hospitalization on caregivers. Caregivers experience a range of positive and negative reactions to patient hospitalization with negative impacts decreasing over time (37) and greater negative emotional experiences (14) relative to the general population. Several factors may explain differences in caregiver’s experience, including severity of psychiatric problems of the patient. Further, caregivers experience a continuum of reactions to caring for patients after hospitalization, with some reporting little disruptions, and others reporting multiple impacts including disruptions in daily activities and stigma. This heterogeneity in reactions may be in part attributable to caregiver and patient characteristics. Caregivers’ reactions may also be influenced by coping style, cultural/ethnic perceptions of mental illness, and beliefs about mental illness.

Practice Implications

Results from this review have implications for practice. Clinicians should include caregivers in treatment and discharge planning to enhance caregivers' capacity to support the patient during and post-hospitalization. Caregivers need education about the negative effects severe psychiatric difficulties may have on them. Such education may normalize and validate the caregivers' reactions and assist caregivers in developing and using coping skills to navigate stresses during and post-hospitalization. Teaching caregivers stress-management skills (e.g., breathing exercises, daily walks) or providing referrals for community resources (e.g., National Alliance of Mental Illness or their local mental health association) may decrease stresses associated with having a patient hospitalized (21, 41).

Educating clinicians about potential caregiver reactions may also improve clinical outcomes for patients. Clinicians need to be aware that caregivers may be dealing with their own issues related to hospitalization or otherwise, and need resources/referrals to access following patient discharge.

Research Implications

Several directions for future research are suggested. First, researchers need a consistent way of operationalizing *impact (positive and negative)* to increase ease of drawing conclusions across studies. Second, new comprehensive conceptual or theoretical models are needed. Existing models focused on stress and coping (18, 30, 31) without considering factors identified in this review (e.g., caregiver and patient characteristics) or cultural and ethnic differences. Of the 29 studies reviewed, three included caregiver race/ethnicity, eight reported patient race/ethnicity, and one focused on cultural and ethnic differences. Additionally, duration of the illness, number of hospitalizations, caregiver satisfaction with hospitalization and staff are factors potentially related to caregiver impact for further study. None of the reviewed studies examined the impact of these factors on caregivers' reactions, whereas research on caregivers of individuals hospitalized for non-psychiatric reasons showed negative impacts on caregivers including financial burden (42), caregiver-patient relationship quality (43), and patient-functioning and caregiver support (44). Third, greater understanding of the heterogeneity in impact of psychiatric hospitalizations on caregivers with a focus on characteristics of patient's illness (e.g., duration of illness, patient's age, degree of risk for harm) is needed. Identifying profiles of caregivers' experiences post-hospitalization could illuminate different ways caregivers are impacted and inform practice.

Conclusion

Caregivers experience positive and negative reactions to patient's psychiatric hospitalization. Research is needed to determine which specific caregiver and patient characteristics are most highly associated with caregiver outcomes, providing a platform for informing interventions, and ultimately, for improving clinical care for patients and their caregivers.

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Table 1

Caregiver and patient demographics in reviewed studies

Reference and country	Caregiver type	Caregiver Race	Patient race; age group	Previously hospitalized	Patient diagnosis
Bauer et al., 2011; Germany (39)	Spouse, n=18; Parent, n=7; Child, n=3; Sibling, n=3; Friend, n=1	<i>nr</i>	<i>nr</i>	<i>nr</i>	Bipolar disorder, n=32
Clarke, 2010; Canada (21)	Mother, n=9; Father, n=1	<i>nr</i>	<i>nr</i> ; adult	<i>nr</i>	<i>nr</i>
Dore et al., 2001; New Zealand (22)	Parent, n=15; Partner, n=13; Other relative, n=9; Friend, n=3; Sibling, n=1	<i>nr</i>	<i>nr</i> ; adult	<i>nr</i>	Bipolar disorder
Gerson et al., 2009; U.S. (23)	Mother, n=9; Father, n=3; Brother, n=1; Aunt, n=1	<i>nr</i>	White, n=5; Hispanic, n=4; Black, n=3; East Asian, n=1; youth and adult	<i>nr</i>	Schizophrenia, n=6; Psychotic disorder NOS, n=6; Schizoaffective disorder, n=1
Hanson, 1995; U.S. (10)	Mother, n=20; Father, n=9; Wife, n=2; Sister, n=2; In-law, n=1	<i>nr</i>	<i>nr</i> ; adult	Average of 5.6	<i>nr</i>
Heru et al., 2004; U.S. (32)	Spouse, n=24; Parent, n=8; Child, n=4; Other, n=2; Sibling, n=1	<i>nr</i>	<i>nr</i> ; adult	<i>nr</i>	Major depressive disorder, n=22; Bipolar disorder, n=17
Heru et al., 2004; U.S. (33)	Spouse, n=11; Parent, n=4; Child, n=2; Other, n=2	<i>nr</i>	<i>nr</i> ; adult	<i>nr</i>	Major depressive disorder, n=10; Bipolar disorder, n=9
Hinnichsen et al., 1999; U.S. (18)	Mother/Stepmother, n=33; Father, n=11; Sibling, n=7; Spouse, n=6; Other family, n=4	<i>nr</i>	White, n=27; Black, n=24; Hispanic, Asian, or Other, n=12; adult	First	Schizophrenia, n=45; Schizoaffective-depressed, n=13; Schizoaffective-manic, n=5; first hospitalization
King et al., 1993; U.S. (13)	Two parents, n=53; Single biological parent, n=26; Biological and stepparent, n=13; Neither parent, n=7	<i>nr</i>	White, n=91; Other, n=6; Black, n=5; youth	<i>nr</i>	Major depressive disorder and suicidal behaviors, n=51; Behavior disorder and suicidal behaviors, n=23; Dysthymia, n=18; Anxiety disorder, n=16; Eating disorder, n=14; Bipolar disorder, n=9; Psychotic disorder, n=2
King et al., 1997; U.S. (12)	Parent, N=74	<i>nr</i>	White, n=57; Black, n=6; Other, n=3; youth	<i>nr</i>	Major depressive disorder, n=48; Conduct disorder, n=16; Dysthymia, n=15; Alcohol use disorder, n=12; Other substance use disorder, n=10; Social phobia, n=10; ADHD, n=9; Generalized anxiety disorder, n=8; Oppositional defiant disorder, n=7; Eating disorder, n=7; Separation anxiety disorder, n=6; PTSD, n=6; Bipolar disorder, n=4; Depressive disorder NOS, n=1
Kjellin et al., 2005; Sweden (26)	Spouse, n=45; Parent, n=42; Child, n=18; Sibling/other relative, n=42; Close friend, n=8	<i>nr</i>	<i>nr</i> ; adult	<i>nr</i>	Schizophrenia, Delusional disorders, Schizoaffective, Schizophreniform disorder or Atypical psychosis, n=48; Affective mood disorder, n=67; Other, n=40
Knox et al., 2007; U.S. (40)	Mother, n=51; Grandmother, n=4; Fathers, n=3; Foster mothers, n=1	<i>nr</i>	White, n=48; Black, n=5; Hispanic, n=4; Biracial/Other, n=4; youth	<i>Nr</i>	<i>nr</i>

Reference and country	Caregiver type	Caregiver Race	Patient race; age group	Previously hospitalized	Patient diagnosis
Lauber et al., 2003; Switzerland (29)	Caregiver (n=64)	<i>nr</i>	<i>nr</i>	<i>nr</i>	Schizophrenia
Moller-Leimkuhler et al., 2005; Germany (34)	Spouse, n=65; Parent, n=17; Brother, n=1	<i>nr</i>	<i>nr</i>	<i>nr</i>	Schizophrenia; Major depressive disorder
Moller-Leimkuhler et al., 2006; Germany (35)	Spouse, n=52; Parent, n=16; Brother, n=1	<i>nr</i>	<i>nr</i>	<i>nr</i>	Schizophrenia; Major depressive disorder
Moller-Leimkuhler et al., 2008; Germany (37)	Spouses, n=51; Parents, n=11	<i>nr</i>	<i>nr</i>	<i>nr</i>	Schizophrenia; Major depressive disorder
Moller-Leimkuhler et al., 2011; Germany (36)	Spouses, n=52; Parent, n=11	<i>nr</i>	<i>nr</i>	<i>nr</i>	Schizophrenia; Major depressive disorder
Ostman et al., 2000; Sweden (28)	Parent, n=35; Spouse, n=26; Child, n=11; Other relative, n=7; Non-relative, n=3	<i>nr</i>	<i>nr</i> ; adult	<i>nr</i>	Psychosis, n=54; Major depressive disorder, bipolar disorder, and anxiety disorders, n=34; Other, n=12
Owens et al., 2011; U.S. (19)	Child, n=22; Spouse, n=5; Parent, n=4; Sibling, n=1	<i>nr</i>	White, n=23; adult	<i>nr</i>	<i>nr</i>
Phelan et al., 1998; U.S. (20)	Spouse, n=29; Parent who lives with patient, n=94; Parent who does not live with patient, n=45; Other, n=27	White, n=154; Black, n=247; Hispanic, n=14	<i>nr</i> ; youth and adult	First	<i>nr</i>
Puotiniemi et al., 2001; Finland (30)	Mother, n=55; Father, n=23; Stepmothers, n=1	<i>nr</i>	<i>nr</i> ; youth	79% first	<i>nr</i>
Puotiniemi et al., 2002; Finland (31)	Mother, n=55; Father, n=23; Stepmother, n=1	<i>nr</i>	<i>nr</i> ; youth	79% first	Emotional and conduct disorders, Major depressive disorder, ADHD, Eating disorders
Ronan et al., 2008; U.S. (16)	Parent, N=60	<i>nr</i>	<i>nr</i> ; youth	<i>nr</i>	Major depressive disorder, n=25; Dysrhythmia, n=13; ADHD, n=7; Adjustment disorders, n=7; Conduct disorders, n=5; Anxiety disorders, n=2; Schizophrenia, n=1
Schmid et al., 2009; Germany (11)	Sibling, N=37	<i>nr</i>	<i>nr</i> ; adult	<i>nr</i>	Schizophrenia, N=37
Snell et al., 2010; U.S. (38)	Mother, n=35; Father, n=2; Non-parental figure n=1	<i>nr</i>	<i>nr</i> ; youth	32% previous	Major depressive disorder, Bipolar II disorder, Adjustment disorder with depressed mood, and depressive disorder secondary to a general medical condition
Solomon et al., 1988; U.S. (24)	Parent, N=13	<i>nr</i>	White, n=16; adult	Average of 9	Schizophrenia
Stueve et al., 1997; U.S. (25)	Caregiver, N = 180	White, n=93; Black, n=43; Hispanic, n=43	<i>nr</i> ; adult	<i>nr</i>	Schizophrenia, Major affective disorder
Thompson et al., 1982; U.S. (27)	Parent, n=52.5; Spouses, n=43.5; Siblings, children, or relative, n=30	White, n=73	<i>nr</i> ; adult	<i>nr</i>	<i>nr</i>

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Reference and country	Caregiver type	Caregiver Race	Patient race; age group	Previously hospitalized	Patient diagnosis
Wagner et al., 1999; U.S. (17)	Biological mother, n=19; biological father, n=6; Stepfather, n=5; Stepmother, n=1; Adoptive mother, n=1; Adoptive father, n=1; Grandmother, n=1	White, n=20; Black, n=3; Hispanic, n=1	White, n=18; Black, n=3; Hispanic, n=2; youth	<i>nr</i>	Serious suicide attempt

nr = not reported

Table 2

Methods and primary caregiver outcomes in reviewed studies

Reference and country	Data Source	Time of Assessment(s)	Primary Outcome(s)
Bauer et al., 2011; Germany (39)	Problem-focused semi-structured interviews	<i>nr</i>	Degree patient ill, Degree of support
Clarke, 2010; Canada (21)	Qualitative interviews	<i>nr</i>	Personal well-being, Stigma
Dore et al., 2001; New Zealand (22)	Semi-structured interviews using the General Health Questionnaire	2 years post-hospitalization	Personal well-being, Stigma, Daily life, Economic strain, Relationship changes, Positive impact
Gerson et al., 2009; U.S. (23)	Qualitative Interviews	During hospitalization	Personal well-being, Stigma
Hanson, 1995; U.S. (10)	Qualitative interviews	<i>nr</i>	Personal well-being
Heru et al., 2004; U.S. (32)	Caregiver Strain scale, visual analogue scales	<i>nr</i>	Personal well-being, Physical health, Positive impact
Heru et al., 2004; U.S. (33)	Family Assessment Device, MOS-36, Caregiver Strain scale, Family Member's Activities of Daily Living Questionnaire	1 year post-hospitalization	Positive impact
Hinrichsen et al., 1999; U.S. (18)	Health and Daily Living Form, Dementia Management Strategies Scale, Patient Rejection Scale, Burden Interview, Symptom Checklist-90	Shortly after admission	Personal well-being, Coping, Caregiver attributes
King et al., 1993; U.S. (13)	Symptom Checklist-90-revised, Social Adjustment Scale-Self Report form, Family Assessment Device	During hospitalization	Personal well-being
King et al., 1997; U.S. (12)	SCL-90-R,SAS-SR	During hospitalization and 6 to 8 months post-hospitalization	Personal well-being, Relationship
Kjellin et al., 2005; Sweden (26)	Semi-structured questionnaire	1 months post-admission	Personal well-being, Daily life
Knox et al., 2007; U.S. (40)	Parenting Stress index	During hospitalization	Personal well-being
Lauber et al., 2003; Switzerland (29)	Semi-structured Interviews	4 years and 3 months after admission	Personal well-being, Daily life, Relationship changes
Moller-Leimkuhler et al., 2005; Germany (34)	Five minute speech sample, Family Questionnaire, Semi-structural biographical interviews, Family Burden questionnaire, Subjective beliefs of competence and control (German questionnaire), NEO Five factor Inventory, Perceived social support (German questionnaire), Lancashire Quality of Life Profile	Baseline, with unspecified details	Personal well-being, Coping
Moller-Leimkuhler et al., 2006; Germany (35)	Qualitative interview, Generalized stress-response, German version of the Ways of Coping Checklist, Subjective beliefs of competence and control, NEO Five factor Inventory, Perceived social support, Subjective well-being, SCL-90-R, Lancashire Quality of Life Profile	1 year post-hospitalization	Personal well-being, Stress, Diagnoses
Moller-Leimkuhler et al., 2008; Germany (37)	Qualitative interview, Generalized stress-response, German version of the Ways of Coping Checklist, Subjective beliefs of competence and control, NEO Five factor Inventory, Perceived social support, Subjective well-being, SCL-90-R, Lancashire Quality of Life Profile	2 years post-hospitalization	Personal well-being, Burden

Reference and country	Data Source	Time of Assessment(s)	Primary Outcome(s)
Moller-Leimkuhler et al., 2011; Germany (36)	NEO Five-factor Inventory, Family Burden Questionnaire, SCL-90	2 years post-hospitalization	Personal well-being, Gender differences
Ostman et al., 2000; Sweden (28)	Semi-structured questionnaire	During hospitalization	Personal well-being, Care, Support
Owens et al., 2011; U.S. (19)	Life experience survey, Burden interview, Brief symptom inventory, Responsible Family Member Evaluation form	During hospitalization	Personal well-being
Phelan et al., 1998; U.S. (20)	Open-ended questions from Social Adjustment Scale	Baseline, with unspecified details and 6 months post-baseline assessment	Stigma
Puotiniemi et al., 2001; Finland (30)	Questionnaires, 93 items formatted using 5-point Likert scales on the following topics: coping, coping demands, coping strategies, coping resources, and social support	During hospitalization, with measures provided, unspecified when returned	Personal well-being, Economic strain, Relationship changes
Puotiniemi et al., 2002; Finland (31)	Questionnaires, open-ended questions about social support	During hospitalization, with measures provided, unspecified when returned	Economic strain, Relationship changes
Ronan et al., 2008; U.S. (16)	SCL-90-R, Life experiences survey, Personal Problem solving inventory, three subscales from the McMaster Family Assessment Device	Three-days post admission	Personal well-being
Schmid et al., 2009; Germany (11)	Narrative interviews	<i>nr</i>	Personal well-being, Relationship changes, Positive impact
Snell et al., 2010; U.S. (38)	Semi-structured interviews, global assessment of each caregiver's emotional state, caregiver interviews	During hospitalization and 2 to 6 weeks post first assessment	Personal well-being
Solomon et al., 1988; U.S. (24)	Qualitative Interviews, Survey item	During hospitalization	Stigma, Economic strain, Relationship changes
Stueve et al., 1997; U.S. (25)	Perceived Burden Scale, Psychiatric Symptom Scale, Caregiver Help Scale, Network Help scale, Network quality scale	Baseline, with unspecified details and 6 to 12 months post baseline	Personal well-being, Stigma
Thompson et al., 1982; U.S. (27)	Index of family members' embarrassment, incomplete sentence blank test	Recruitment began six months post-discharge, other details unspecified	Personal well-being, Economic strain, Burden
Wagner et al., 1999; U.S. (17)	Reaction to Suicide attempt scale (modification of statement rating scale), Family History Interview	During hospitalization	Personal well-being

nr = not reported