



# Positive and negative impacts of schizophrenia on family caregivers: a systematic review and qualitative meta-summary

Nao Shiraishi<sup>1</sup> · Jacqueline Reilly<sup>2</sup>

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## Abstract

**Purpose** Schizophrenia places a heavy burden on the individual with the disorder, as well as on his or her family; this burden continues over the long course of the disease. This study aimed to provide an overview of the positive and negative impacts of schizophrenia on family caregivers.

**Methods** From April to June 2017, two investigators conducted a systematic review and meta-summary of studies obtained from five electronic databases and the footnotes and citations of eligible studies. Qualitative studies that explored the experiences of family caregivers of individuals with schizophrenia were included. Study findings published between 1993 and 2017 were extracted and synthesised using narrative and summative approaches.

**Results** After the removal of duplicates, independent reviewers screened 864 records. Subsequently, 46 full-text articles were assessed for eligibility and 23 papers were included in the synthesis. Negative impacts identified were traumatic experiences, loss of expectation of life and health, lack of personal and social resources, uncertainty and unpredictability, family disruption, conflict in interpersonal relationships, difficulty in understanding, and stigma and heredity. Meanwhile, the positive impacts identified were family solidarity, admiration, affirmation, affection, compassion, learning knowledge and skills, self-confidence, personal growth, and appreciation.

**Conclusions** Analysis of the studies suggested that family members of individuals with schizophrenia face a series of traumatic situations during the course of the illness. Their subsequent experiences can be conceptualised as a continuous circle of caregiving, in which the positive impacts can be centrally positioned within the negative impacts.

**Keywords** Qualitative synthesis · Caregiving process · Caregiver burden · Caregiver benefits · Mandala

## Introduction

The development of schizophrenia commonly occurs in early adulthood, and individuals may live for many years with disabilities. As a result, the burden of this disorder has been ranked 11th among 301 diseases and injuries [1]. These

disabilities often impede patients from leading the lives that they expected during their premorbid states, due to deterioration in social and occupational functioning [2]. During an illness course of up to 25 years, approximately 50% of people with schizophrenia fail to achieve satisfactory recovery in terms of their symptoms and social functions [3]. This long recovery period imposes a heavy burden on both the individuals with schizophrenia and their family members, who usually play a major role in caregiving [4]. Therefore, it is important to investigate the impact that schizophrenia has on the family to improve the mental well-being of informal caregivers.

Family burden in schizophrenia has certain established domains, of which family relations and social interactions are important. In 1966, Hoenig and Hamilton categorised burdens of care into objective and subjective domains [5]. Objective burdens reflect the tangible aspects of caregiving, such as financial issues, while subjective burdens reflect how

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✉ Nao Shiraishi  
nao-shiraishi@umin.ac.jp

<sup>1</sup> Department of Psychiatry and Cognitive-Behavioral Medicine, Nagoya City University Graduate School of Medical Sciences, 1 Kawasumi, Mizuho-cho, Mizuho-ku, Nagoya 467-8601, Japan

<sup>2</sup> Department of Public Health, University of Glasgow, 1 Lilybank Gardens, Glasgow G12 8RZ, UK

caregivers perceive and evaluate their situations in relation to an illness. Subsequent research has supported Hoenig and Hamilton's theory, which became the basis for measures of burdens of care [6–8]. By means of such measures, quantitative studies have extensively investigated both burdens [4, 9]. Caqueo-Urizar et al. suggested 'role theory' and 'systemic theory' as new conceptions regarding care in schizophrenia [9]. Role theory considers the unmet expectations of caregivers from an ill person as a major cause of their mental burdens. Individuals have their own roles within a family and are expected to fulfil these roles. However, schizophrenia often makes it difficult to satisfy these expectations, which has a negative impact on family relationships. The systemic theory positions a family within its social continuum. Care burden can also be understood within interactions in the hierarchy of individual, familial, local, and national substructures. For example, caregivers tend to feel burdened while interacting with inadequate health services in the community.

Compared to the family burden, there is paucity of studies on caregiver benefits in schizophrenia. This suggests that the negative nature of caregiving in schizophrenia renders obtaining sufficient empirical data to reveal overall positive experiences difficult [10, 11]. In 1996, Szmukler et al. conceptualised the following benefits from caring for a patient with a serious mental illness: 'rewarding personal experiences' and 'good aspects of the relationship with the patient' [12]. Chen and Greenberg reported that more than half of 560 caregivers benefited from becoming conscious of inner strengths and new meanings in their lives [13]. These gains were positively associated with the supportive relationships that others had to the caregivers.

Burden of care is defined as a multi-faceted concept comprising intrinsic and extrinsic elements and is influenced by the supply and cost of health interventions and services [14, 15]. Awad and Voruganti have contributed to the development of a clear definition of burden of care by offering a comprehensive, but non-systematic, review of the burden of schizophrenia on informal caregivers. Tungpunkom et al. conducted a systematic review of family experiences in caring for an ill relative. However, Tungpunkom et al.'s study did not focus on care burden, but rather synthesised care experiences from five outcomes of interest, including needs, coping, and help seeking [16]. The synthesis of the different outcomes complicates the interpretation of their conclusions for practical use. In terms of help seeking, Cairns et al. conducted a meta-synthesis of 13 qualitative studies of families of patients with first-episode psychosis [17]. Qualitative reviews conducted by Klages et al. [18] and Lewis [19] exclusively investigated the experiences of parents and partners, respectively, who cared for ill relatives. Therefore, we suggest that it is important to define the entire set of elements that not only negatively, but also positively, impacts

all informal caregivers, which could help families with a member with schizophrenia spend their lives with increased feelings of satisfaction, gratitude, and enjoyment over the long duration of the disorder. In this study, we aimed to formulate a comprehensive concept to show the relationships between the positive and negative impacts that this disorder has on family caregivers by collating qualitative findings from relevant studies.

## Methods

In this study, a systematic review and a meta-summary were conducted by two reviewers (a psychiatrist and a qualitative researcher). The meta-summary is a method of qualitative synthesis developed by Sandelowski and Barroso to approximate elemental themes by integrating the sum of findings of qualitative studies according to a systematic scheme [20]. The choice of the approach depends on the type of information the review authors intend to produce in qualitative evidence synthesis. Since this synthesis aimed to answer a clinical question related to health-care interventions, an integrative-type method (e.g. meta-summary) was appropriate [21]. The research protocol is available online (CRD42017073325 with PROSPERO).

## Study selection criteria

### Types of studies

The reviewers included primary studies that used qualitative approaches to collecting data and analysed data with qualitative methods. The following studies were excluded: (1) studies without qualitative data collection; (2) studies that collected data with qualitative approaches, but did not conduct a qualitative analysis; (3) studies that collected qualitative data via a questionnaire with a priori domains for the burden of care; (4) reviews with qualitative methods; (5) mixed-methods studies in which the results could not be distinguished between qualitative and quantitative findings; (6) mixed-sample studies where it was impossible to discern the origin of findings between types of participants; (7) qualitative studies in which participants were not human beings, such as text data in mass media; and (8) empirical and narrative works that had not undergone a peer-review processes.

### Types of participants

A caregiver was defined as an adult aged 18 years or older caring for his or her family member with schizophrenia. Family relationships included parents, siblings, spouses, or other relatives. Studies were excluded when they were

concerned with: (1) affected individuals or health-care workers without family caregivers; (2) childhood schizophrenia; (3) psychosis in which schizophrenia could not be separated from other psychotic disorders; and (4) diseases other than psychotic disorders.

### Types of phenomena of interest

The phenomena of interest were the positive and negative impacts on someone who shares his or her life with an individual with schizophrenia. We limited the search to studies conducted after 1993 because a second-generation antipsychotic, risperidone, was introduced in that year and atypical antipsychotics have since been approved for use globally [22]. The availability of these new medications has contributed to recovery from schizophrenia with less severe extrapyramidal side effects, which could alter the experiences of caregivers of people with schizophrenia [23]. We excluded studies that (1) did not aim to achieve an in-depth understanding of the defined phenomena of interest; (2) exclusively investigated a specific aspect of caregiving (e.g. stigma, needs, or coping).

### Search strategy for identification of studies

#### Electronic searches

We conducted searches of the following electronic bibliographic databases: (a) MEDLINE, Ovid; (b) MEDLINE In-Process and Other Non-Indexed Citations, Ovid; (c) Embase, Ovid; (d) Cumulative Index to Nursing and Allied Health (CINAHL), EBSCOhost; (e) PsycINFO, EBSCOhost; and (f) Web of Science Core Collection, ISI. Search terms were developed for database searching with English language requirements (Online Appendix 1).

#### Other searches

Reference lists of eligible studies were examined to detect relevant reports unidentified in the electronic search. We also examined the systematic reviews conducted by Tungpunkom et al. [16], Klages et al. [18], and Lewis [19] to identify any reports that they included or excluded that were not identified in our electronic search or reference list check. In addition, Web of Science All Databases was used to follow up relevant works that had cited eligible studies. Scopus was also used to verify the results of citation chasing.

### Quality of eligible studies

The two reviewers independently assessed the quality of selected studies according to the ‘Checklist for Qualitative Research’ in the Joanna Briggs Institute (JBI) critical

appraisal tools [24]. Discrepancies between the assessment results were resolved through discussion at the weekly research meetings that the reviewers held. This checklist was originally developed for use in the institute’s approach, ‘meta-aggregation’. Meta-aggregation and meta-summary share a systematic scheme to integrate and quantify qualitative findings [25].

### Data extraction

After completing the critical reading, the first reviewer extracted findings from the included studies and the second reviewer cross-checked the results against her own extracted findings. The extraction was conducted using the worksheets that included information on cultural factors. The two reviewers resolved disagreements on the extraction through debate during the weekly research meetings. The data extraction method was modified from Sandelowski and Barroso’s method [20] and comprised the following steps: (1) repeated reading of all included articles to understand the overall meaning and become familiar with the data; (2) developing the first and second editions of extracts based on the themes and subthemes of the articles, respectively; and (3) dividing the second edition into the smallest unit of structure of findings.

### Data synthesis

Comparing similarities and differences, and the relationships between them in the extracted findings, the first reviewer categorised topical meanings. Subsequently, they were abstracted into subthemes and themes to represent the key meaning and comprehend the contents. These interpretive processes were cross-checked against the second reviewer’s own categorisation and abstraction. Disagreements on the interpretation were resolved through debate during the weekly research meetings. The meta-summary tabulated the themes with the following proportions [20]. The proportional frequency of qualitative findings (PF-QF) was computed by dividing the number of papers with a particular subtheme by the total number of papers. The PF-QF was used to compare the extent of the subthemes. The proportional intensity of thematic reporting (PI-TR) was computed by dividing the number of subthemes contained in one paper by the total number of subthemes in all papers reviewed. The PI-TR represented the contribution of each study to all themes.

As a final product of the meta-summary, a conceptual model was created as a figure to provide an overview of the overall impact of schizophrenia on family caregivers. The conceptual diagram connected themes and subthemes on the grounds of empirical and/or theoretical relationships between them [26].

## Results

The literature search was performed between 29 April 2017 and 9 June 2017 (Fig. 1). The electronic and other searches yielded 1355 records, from which the removal of duplicates reduced the sum to 864 records. Title and abstract screening retained 46 articles whose full texts were assessed for eligibility. Subsequently, the first and second reviewers independently conducted the eligibility assessment of all 46 articles. Consequently, 23 articles were selected to undergo critical appraisal for qualitative research [27–49]. The other articles were excluded from the study for several reasons. Five studies were excluded because the burden of care was assessed in accordance with a priori domains [50–54]. Four studies did not discern

the origin of findings between affected individuals and their caregivers [55–58]. The diseases covered in two studies included borderline personality disorder and childhood schizophrenia [59, 60]. Other excluded studies had phenomena of interest that were different from an in-depth understanding of experiences in caregiving from the caregivers' perspectives [61–72].

## Quality assessment

The two reviewers independently conducted critical appraisal of the eligible studies (Online Appendix 2) and determined whether they met each criterion. Eight studies (34.8%) met Criterion 6 (context). Wiens and Daniluk stated both the cultural and theoretical orientations that the researchers had towards their study [39]. Both orientations

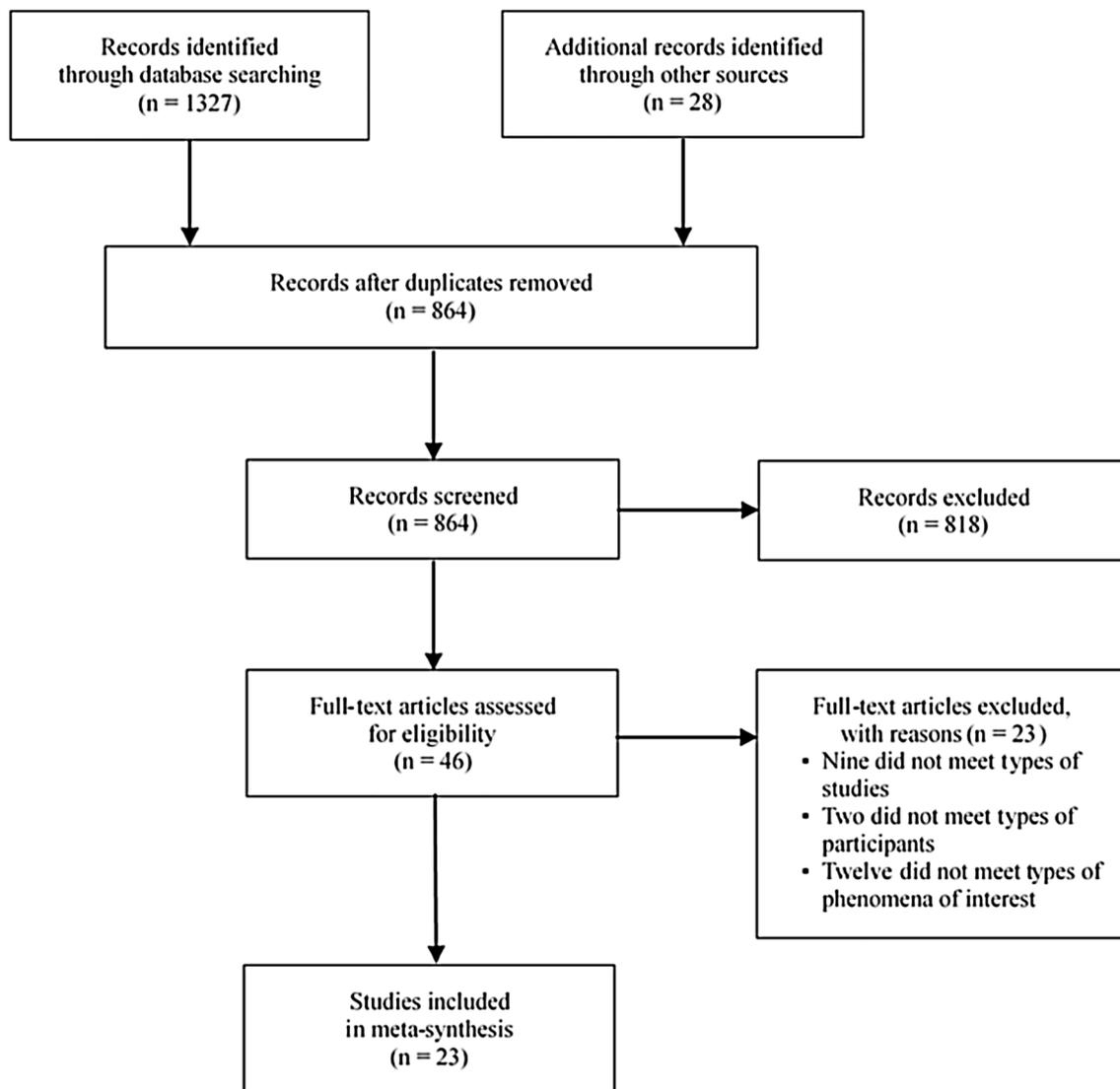


Fig. 1 Flow diagram showing the design of the study

of a research group had a potential influence on Tuck et al.'s study [29]. The other studies meeting Criterion 6 located the researchers' language and/or professional backgrounds. Criterion 7 (impact of investigator) was fulfilled by 12 studies (52.2%). The relationship between researchers and study participants was reported by Huang et al. [37] and Molefi and Swartz [41] and was addressed by Mizuno et al. [42]. In the other studies meeting Criterion 7, the researchers stated the critical examination of the influence introduced by themselves on the research process and/or the data interpretation. Conversely, seven studies (30.4%) did not satisfy Criterion 9 (ethics). Despite the ambiguity, all seven studies were conducted in settings associated with health services or medical care. Therefore, it is reasonable to assume that the research had been approved by an appropriate ethics review board. Jungbauer et al. [47] did not meet Criterion 2 (appropriateness of research design). Although they did not clearly propose a research question, it seemed to be incorporated into the statement of research methodology. Molefi and Swartz did not provide sufficient description to fulfil Criterion 4 (data analysis) [41]. This flaw of the study was possibly influenced by the journal's space limitations.

### Meta-summary

Data extraction resulted in 474 findings as the smallest unit of structure from the included studies, the characteristics of which are shown in Table 1. Table 2 shows that the positive and negative impacts of schizophrenia comprise the themes of a caregiving process, six burdens of care, and caregiver benefits. The PF-QF indicated that nearly 50% of the included reports contained the subthemes of a diagnosis of schizophrenia and uncertainty regarding future care, followed by those of loss of expectations for the relative, loss of caregivers' personal lives, unpredictability of pathological behaviour, and understanding the cause of schizophrenia. Addressing cultural factors or cultural differences in the synthesis, in-depth descriptions for each of 33 subthemes were created in accordance with the research protocol. Since the main purpose of this study was to provide an overview of the illness impacts on family caregivers, we do not present the descriptions here.

The process can be divided into six subtheme stages, during which family members were likely to be burdened by experiences related to the development of the relative's illness. Traumatic experiences start before the onset of mental illness and proceed through to manifestation of mental illness. Affected relatives are usually diagnosed with schizophrenia at a point between manifestation of the mental illness and a crisis situation, after which they may enter a lifelong course of treatment. From the family members' standpoint, this process results in ongoing caregiving. However, illness exacerbations can cause a return from ongoing

caregiving to crisis situations. A randomised controlled trial demonstrated that, after remission induced by antipsychotics for first-episode psychosis, 43% of the patients who discontinued the treatment experienced a second episode within 18 months. Even when the medication was continued, 21% of the patients relapsed [73]. A cohort study indicated that the relapse rates were 78% and 86% in patients who had recovered from their second and third episodes, respectively [74]. Thus, a cyclical structure is present in the relationship between the two stages, within which family members bear the seven negative impacts.

The positive aspects of caring for a relative with schizophrenia comprised nine subthemes. Affection is referred to most often in all studies, followed by compassion, family solidarity, self-confidence, personal growth, learning knowledge and skills, affirmation, admiration, and appreciation. The PF-QF of the positive impacts tended to be lower than that of the negative impacts. The nine concepts can be considered to be centrally located within the continuous cycle of caregiving because positive experiences in caregiving were associated with the metacognitive ability that family members have (i.e. capacity for a panoramic view of caregiving experiences) [75] and high-level constructs of the positive aspects of caregiving related to inner strengths were likely to be independent from objective and subjective burdens [76]. The centralisation of positive aspects can also be explained by similarity to religious teachings. Especially in Buddhism, a path to reach the state of enlightenment or nirvana in the endless circle of agonies of life is visualised in sacred art, mandala [77]. Buddhist families in Thailand seemed to find more positive values in interpersonal relationships, involving compassion, through their religious belief [35, 49, 70]. Figure 2 illustrates the illness impacts on family caregivers that resembles the structure of mandala.

### Discussion

This is the first study, to our knowledge, to present a whole picture of the positive and negative impacts of schizophrenia on family caregivers by synthesising qualitative evidence. During the first episode of schizophrenia, family members of the individual with schizophrenia tend to experience a series of traumatic events. Subsequently, they encounter an ongoing cycle of caregiving. Within this continuous care cycle, negative impacts of the illness are experienced, including uncertainty and unpredictability, loss of expectation of life and health, lack of personal and social resources, difficulty in understanding, stigma and heredity, family disruption, and conflict in interpersonal relationships. The positive aspects of caregiving emerge at a central position within this circle because family members can recognise the values of family solidarity, admiration, affirmation, affection, compassion,

**Table 1** Characteristics of the included studies

Study	Setting	Care givers	Care recipients	Methods	Purpose of study
Gerace et al. [55]	USA A support group or psychoeducation workshops	14 siblings Age: 28–45 years; mean = 35 years 11 females; 3 males 13 Caucasians and 1 African-American	14 ill siblings Age: 24–50 years; mean = 33 years 7 females; 7 males	Qualitative case study design Audiotaped semi-structured interviews Content and thematic analyses	To explore siblings' experiences with a mentally ill brother or sister
Ryan [56]	Canada One community support group	5 mothers Age: 50–62 years Caucasian	5 adult children Age: 22–38 years One daughter and four sons Illness duration: 6–20 years	Ethnography Tape-recorded Ethnographic interviews Thematic analysis using Spradley's approach	To explore and describe the experience of mothers living with schizophrenic adult children
Tuck et al. [57]	USA Referrals by mental health professionals and the Alliance for the Mentally Ill	9 parents 7 females; 2 males 1 African American and 8 whites	Adult children All males	Phenomenology Audiotaped interviews Thematic analysis based on the approach developed by four authors	To explore the phenomenon of caring for an adult child with schizophrenia in a way that could preserve the situated wholeness of the experience
Howard [58]	USA Referrals by women who had participated in a study of maternal caregiving	12 fathers Age: 49–76 years; mean = 67.7 years	Adult children Age: 24–42 years; mean = 35.8	Descriptive design Taped interviews with research memos and literature Thematic analysis using a constant-comparative method	To determine the experience of fathers of adult children with schizophrenia and to assess the extent to which they engage in caregiving
Ip and Mackenzie [59]	China (Hong Kong) One community psychiatric nursing service in a local mental hospital	8 family caregivers Age: 29–70 years; mean = 44.9 years 3 mothers, 2 sisters, 2 wives, and 1 husband	Outpatients Illness duration: 3–20+ years	Descriptive design Audiotaped semi-structured interviews Thematic analysis base on Burnard's approach	To gain an understanding of the experience of caregiving for a relative who has serious mental illness and is living at home
Pejler [60]	Sweden The move from a psychiatric hospital to a home-like setting	8 parents 3 couples, 1 mother, and 1 father	6 patients Age: 30–47 years; mean = 41.6 years	Phenomenological hermeneutics Audio-taped narrative interviews Three-stage structural analyses developed by two authors	To illuminate the meaning of parental caregiving of a son or daughter with severe mental illness living in a care setting
Rungreangkulkij and Chesla [61]	Thailand One public psychiatric hospital in a northeastern province	12 mothers Age: 40–64 years; mean = 52 years	12 adult children Age: 21–40 years; mean = 28.3 years Illness duration: 3–13 years; mean 6.5 years Outpatients	Interpretive phenomenology Audiotaped interviews Thematic interpretation	To explore culturally specific beliefs and patterns of response

**Table 1** (continued)

Study	Setting	Care givers	Care recipients	Methods	Purpose of study
Jungbauer et al. [62]	Germany Inpatient, day care, and outpatient psychiatric facilities	52 spouses Age: 22–72 years; mean = 46 years 24 females; 28 males 21% with a history of mental illness	Patients Age: mean = 45 yrs 8% in inpatient psychiatric treatment	Grounded theory Tape-recorded narrative interviews with contact protocols Analysis used in Grounded theory as developed by Strauss and Corbin	To understand caregivers' living situations as manifested in their narratives and everyday descriptions
Nystrom and Svensson [63]	Sweden Four local branches of the Swedish National Fellowship for Schizophrenia	7 fathers Age: 63–78 years	Adult children Middle-aged Diagnosed at the age of 16–19	Hermeneutics Audiotaped one-to-one interviews Interpretative and thematic analyses	To analyse and describe lived experiences of being a father of an adult child with schizophrenia
Stalberg et al. [64]	Sweden One university hospital's psychiatric centre	16 siblings Age: 16–55 years; mean = 31 years 8 females; 8 males	14 patients Age: 20–52 years; mean = 32 years 5 females; 9 males	Grounded theory Audiotaped semi-structured interviews Thematic analysis	To explore how schizophrenia patients' siblings perceive the sibling relationship and their role, using a psychological approach
Sethabouppha and Kane [65]	Thailand One large psychiatric hospital in Chiang Mai	15 family caregivers Age: 32–65 years; mean = 51 years 9 females; 6 males 9 (grand-) parents, 3 siblings, 2 spouses, and 1 daughter	15 adult children Age: 22–50 years; mean = 33 years 7 female; 8 males Outpatients	Phenomenology Tape-recorded interviews with notes and journaling Phenomenological qualitative and thematic analyses	To explore the meaning of the lived experiences of Thai Buddhist caregivers
Barnable et al. [66]	Canada One local hospital in an Atlantic city	6 siblings Age: 35–64 years	Ill siblings Age: 25–59 years	Hermeneutic phenomenology Audiotaped semi-structured interviews Thematic analysis	To gain a rich understanding of the life experience of siblings of individuals with schizophrenia
Huang et al. [67]	Taiwan Community-based psychiatric home visiting services	10 family caregivers Age: 42–75 years; mean = 61.2 years 5 females; 5 males 4 mothers, 3 fathers, 1 wife, and 2 husbands	10 adult children Age: 23–58 years; mean = 38 years 2 daughters, 5 sons, 2 wives, and 1 husband Illness duration: 3–26 years; mean = 15.9 years	Phenomenology Tape-recorded face-to-face interviews with field notes Thematic analysis using Colaizzi's seven-step procedure	To explore the experiences of carers who live with someone with long-term schizophrenia within the cultural context of Taiwan
Mhaule and Niswane-Lebang [68]	South Africa Clinical records by community psychiatric nurse in a rural area	12 family caregivers Age: 30–60 years All females 6 mothers, 2 sisters, 1 child, and 3 others	Outpatients	Phenomenology Audiotaped individual interviews with field notes Thematic analysis using constant comparative method	To explore and describe the experiences of caregivers of individuals suffering from schizophrenia to share the findings with the mental health-care authorities in Mpumalanga Province

Table 1 (continued)

Study	Setting	Care givers	Care recipients	Methods	Purpose of study
Wiens and Damiluk [69]	Canada Support groups and community mental health clinics in a metropolitan West Coast city	6 fathers 4 in their late 40 s and 50 s, 1 in his 60 s, and 1 in his early 70 s Caucasian	6 adult children Age: 18–31 years 5 sons and 1 daughter 4 diagnosed for 4 years and 2 for 8 years	Phenomenology Audio-taped interviews with process notes Thematic analysis using Colaizzi's seven-stage approach	To provide a greater understanding of the experience of fathering a young adult child with schizophrenia by giving voice to fathers whose children had been diagnosed within the past 10 years
Mizuno et al. [70]	Japan Two psychiatric hospitals and rehabilitation facilities in two prefectures	12 husbands Age: 22–77 years; mean = 50.8 years	12 wives Age: 47.8 years; mean = 47.8 years Illness duration: 7–41 years; mean = 18 years	Descriptive design Tape-recorded face-to-face semi-structured interviews Content analysis	To describe and understand the caregiving experiences of husbands living with spouses with schizophrenia
Molefi and Swartz [71]	South Africa One psychiatric hospital in the Western Cape	11 family caregivers 1 in her 20 s, 5 in their 40 s, and 4 in their 50 s 9 mothers, 1 father, and 1 sister 6 Coloured and 5 Black Africans	Patients	Qualitative exploratory design Digitally recorded face-to-face semi-structured interviews Thematic analysis	To investigate the experiences of South African families with schizophrenia, their perception and understanding of schizophrenia as an illness, and the interface between these families and medical practitioners
Mizuno et al. [72]	Japan Two local family associations	11 family caregivers Age: 37–76 years; mean = 65.1 years All females Mother, sister, wife, and sister-in-law	14 patients Age: 27–84 years; mean = 47.2 years Illness duration: 10–61 years; mean = 23.6 years	Descriptive exploratory design Digitally recorded focus group interviews Content analysis	To explore families' experiences of persons with schizophrenia, towards which the general public still has prejudice
Saunders [73]	United States One community resource and service centre in the impoverished Hispanic communities in Texas	10 family caregivers Age: 48–59 years; 54.8 years All females 6 mothers, 3 siblings, and 1 cousin Hispanic (Mexican)	Care recipients	Qualitative exploratory design Audio-recorded monthly interviews for 6 months with field notes and journaling Content analysis	To explore the perspectives of Hispanic caregivers as they provided the day-to-day care for their family member with schizophrenia over a 6-month period
Gater et al. [48]	United States Private clinicians in Philadelphia, Chicago, and New Orleans	19 family caregivers Age: 28–69 years; mean = 51.6 years 15 females; 4 males 6 parents, 6 siblings, 2 spouses, 3 children, 1 nephew, and 1 aunt	19 patients Age: 21–82 years; mean = 51.8 years 12 females; 7 males Illness duration: 3–42 years; mean = 16 years	Grounded theory Audio-taped face-to-face semi-structured interviews Comparative analysis	To investigate the subjective experiences of informal caregivers of people with schizophrenia and to develop a preliminary conceptual model outlining the impact of caregiving on their daily lives

**Table 1** (continued)

Study	Setting	Care givers	Care recipients	Methods	Purpose of study
McAuliffe et al. [74]	Ireland Referrals by one consultant psychiatrist	6 parents Age: 60–77 years; mean = 66 years 5 mothers and 1 father Caucasian	6 adult children Age: 27–45 years; mean = 37.2 years 2 females; 4 males	Descriptive qualitative design Tape-recorded semi-structured interviews Thematic analysis	To explore the experience of parents living with and caring for their adult children with schizophrenia
Landon et al. [75]	New Zealand One non-governmental agency	6 parents Age: 58–73 years; mean = 68.8 years 5 mothers and 1 father European	Adult children All sons	Descriptive design Digitally recorded semi-structured interviews Thematic analysis	To offers a holistic view of the caregiving experience in the New Zealand context
Yang et al. [76]	Taiwan One psychiatric hospital in a central area	10 siblings Age: 30–65 years; mean = 44.9 years 7 females; 3 males	Inpatients	Descriptive design Audio-recorded semi-structured individual interviews Content analysis	To understand siblings' experiences as the primary caregiver of patients with schizophrenia in Taiwan

learning knowledge and skills, self-confidence, personal growth, and appreciation as they free themselves from being solely concerned with the seven negative impacts.

Considering the most rigorous subset of excluded qualitative studies by Hernandez and Barrio [54] and Saunders and Byrne [50], it was confirmed that the present review offers a more comprehensive concept of the negative impacts of schizophrenia on family caregivers. Despite the fact that our exclusion criteria might be restrictive for qualitative research, all the themes represented in these studies have been replicated and restructured by the proposed results. Quantitative studies have also shown the associations of the negative impacts identified with the following clinical factors: psychotic symptoms [78, 79], violence [80], negative and cognitive symptoms [79], social support [81], knowledge and stigma [82, 83], and family relationships [84]. Furthermore, a higher level of abstraction of caregiving benefits in the included studies invites a new perspective of the relationship between positive and negative impacts during continuous caregiving. The study by Gater et al. conceptualised the potential benefits to caregivers, but their theme of ‘benefits of caregiving’ mixed practical and more abstract benefits [48]. Our review integrates practical advantages into higher-level constructs, as the ill relative’s help with household chores was abstracted into the theme of appreciation. The integration process helped us locate similarities between abstracted findings and religious beliefs and the central conceptualisation of the positive aspects of caregiving. Compared to ‘rewarding personal experiences’ and ‘good aspects of the relationship with the patient’ noted in Szmukler et al.’s study, the nine benefits identified in this study could be clustered into three domains [12]. Relationships could mature by favourable appraisal of interpersonal relationships: family solidarity, affection, and compassion. Meanwhile, mastery could develop by favourable appraisal of inner strengths: learning knowledge and skills, self-confidence, and personal growth. Maturing relationships and developing mastery might be enhanced by favourable appraisal of mutual behaviour: affirmation, admiration, and appreciation.

This study is subject to limitations related to methodological issues in the synthesis of qualitative evidence. First, the analysis and coding processes were conducted by the two researchers without further external and iterative validation (e.g. multidisciplinary interpretation). In practice, the first reviewer’s interpretation was checked against the second’s. Additional verification could increase the validity of the research processes. However, discussion at research meetings was employed as a means to resolve interpretive discrepancy and ensure interpretive validity. Second, inadequate reporting may have adversely influenced the process of data extraction. When an author provided relatively thin descriptions of the analysed data, the interpretation was

**Table 2** Meta-summary of the positive and negative impacts of schizophrenia on family caregivers

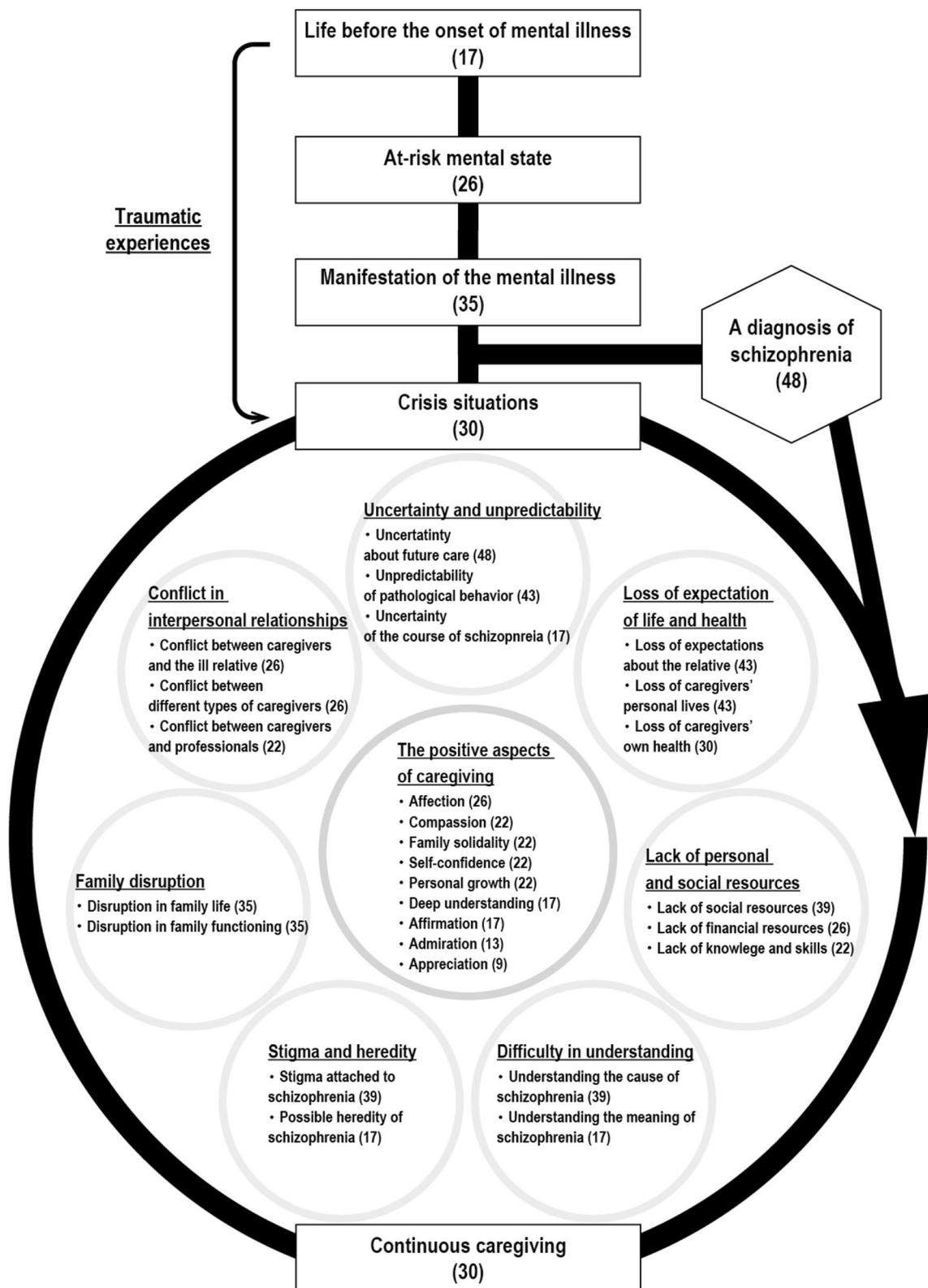
Themes and subthemes with PF-QF/PI-TR	%	Garace et al. (1993)	Howard (1998)	Ip and Mckeenzie (1998)	Mizuno et al. (2011)	Molero and Swartz (2011)	Mizuno et al. (2013)	Saunders (2013)	McAuliffe et al. (2014)	Landon et al. (2016)	Yang et al. (2016)	Tuck et al. (1997)	Pylet (2001)	Rungtanyakuljij and Chesda (2001)	Nystrom and Svensson (2004)	Schubert and Kane (2005)	Barnble et al. (2006)	Huang et al. (2009)	Mhande and Niswam-Lehang (2009)	Wiers and Daniluk (2009)	Jungbauer et al. (2004)	Suhberg et al. (2004)	Cater et al. (2014)	Ryan (1993)
Included studies sorted by methodological types:																								
▪ Descriptive design (n = 10)																								
▪ Phenomenology and hermeneutics (n = 9),																								
▪ Grounded theory (n = 3)																								
▪ Ethnography (n = 1)																								
Traumatic experiences																								
▪ Life before the onset of mental illness	17																							
▪ At-risk mental state	26																							
▪ Manifestation of the mental illness	35																							
▪ Crisis situations	30																							
▪ A diagnosis of schizophrenia	48																							
▪ Continuous caregiving	30																							
Loss of expectation of life and health																								
▪ Loss of expectations for the relative	43																							
▪ Loss of caregivers' personal lives	43																							
▪ Loss of caregivers' own health	30																							
Lack of personal and social resources																								
▪ Lack of knowledge and skills	22																							
▪ Lack of social resources	39																							
▪ Lack of financial resources	26																							
Uncertainty and unpredictability																								
▪ Uncertainty about future care	48																							
▪ Uncertainty of the course of schizophrenia	17																							
▪ Unpredictability of pathological behaviour	43																							
Family disruption																								
▪ Disruption in family life	35																							
▪ Disruption in family functioning	35																							
Conflict in interpersonal relationships																								
▪ Conflict between caregivers and the ill relative	26																							
▪ Conflict between different types of caregivers	26																							
▪ Conflict between caregivers and professionals	22																							
Difficulty in understanding																								
▪ Understanding the meaning of schizophrenia	22																							
▪ Understanding the cause of schizophrenia	43																							
Stigma and heredity																								
▪ Possible heredity of schizophrenia	17																							
▪ Stigma attached to schizophrenia	39																							
The positive aspects of caregiving																								
▪ Family solidarity	22																							
▪ Admiration	13																							
▪ Affirmation	17																							
▪ Affection	26																							
▪ Compassion	22																							
▪ Learning knowledge and skills	17																							
▪ Self-confidence	22																							
▪ Personal growth	22																							
▪ Appreciation	9																							

PF-QF proportional frequency of qualitative finding, PF-IR proportional intensity of thematic reporting

more likely to depend on the reviewers' perspective. A lack of information also makes low study quality less detectable during quality assessment [85]. Third, conceptual breadth might be undermined by the exclusion of studies with low-quality methodology and reporting (e.g. unpublished academic work). There is controversy over whether studies with low methodological quality should be excluded from synthesis. Methodologically flawed studies do not always equate to a lack of deep understanding, so they might offer novel insight into the phenomena of interest [86]. However, empirical evidence suggests that additional interpretation of findings after excluding studies with inadequate reporting quality in two systematic reviews was not missed [87].

Our results contribute to the promotion of the mental well-being of families with a member with schizophrenia. Family intervention has been established as an

evidence-based practice to reduce relapse and rehospitalisation in patients with this disorder [88]. However, numerous such interventions were not sufficient to accentuate the beneficial effects of caregiving on family members [14]. In this review, we propose a set of caregiver benefits alongside seven adverse impacts, which can be used as a theoretical method to design health-service interventions for users and their relatives. We propose that, to strengthen the benefits, health-care interventions should aim at encouraging favourable appraisal of interpersonal relationships and help bolster inner strengths. Before creating the interventions, future research is needed to develop a new assessment measure to establish the validity of the study findings and to assess how patient recovery is associated with positive impacts on family caregivers.



**Fig. 2** Conceptual diagram of positive and negative impacts of schizophrenia on family caregivers. Figures in parentheses represent the proportion of the number of included studies with a particular subtheme by the total number of all the studies

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## Compliance with ethical standards

**Conflict of interest** We declare no competing interests.

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