



Content analysis of the emotions affecting caregivers of relatives with schizophrenia

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Abstract

Understanding the emotions of caregiving is key for supporting families with an ill relative. This study explored how negative and positive emotions were experienced by caregivers and the meaning they attached to both types of emotions with regard to schizophrenia. Content analysis was conducted by two independent reviewers to extract and code family caregivers' emotions according to Plutchik's wheel of emotions. The findings of 23 qualitative studies identified in a previous systematic review were used for the analysis. The proportion of the emotions that were negative and positive was calculated by the effect of the illness. Two reviewers also synthesized the qualitative findings to describe the meaning of the emotional content. Regarding the negative effects of schizophrenia, the dominant emotions were fear, sadness, anger, followed by shame, and guilt. These negative emotions detached the caregivers from their relationships with their family, community, and society. Additionally, such emotions involved them in the past and the future and prevented them from living in the present. Regarding positive effects, the essential emotions were trust, joy, and love. The positive effects were described using three domains of favorable appraisal (i.e., interpersonal relationships, inner strength, and mutual behavior), in which the caregivers could develop a sense of belonging from the relationships with health professionals and the courage to manage difficult reality. Understanding the emotions of caregivers shows professionals how to emotionally support family members during the continuous process of caregiving, which may allow them to identify the meaningful aspects of the care experience.

Keywords Psychosis · Emotional content · Qualitative analysis · Caregiving benefits · Mandara

The burden of schizophrenia exerts serious effects on both the affected individual and their family members. After experiencing traumatic events in the prodromal and early stages of psychosis, family members engage in continuous caregiving, during which time they experience negative emotions due to the effects of the illness. Despite this adversity, family members are positively affected by caring for a relative with schizophrenia (Shiraishi & Reilly, 2019). The emotions experienced during the process of caregiving are considered key for family members finding positive meaning in care experience.

Emotions are an essential, internal experience and define psychological distress and well-being. Plutchik (1980) proposed eight basic emotions that are common in both animals and humans and shared across cultures: joy, sadness, trust, disgust, fear, anger, surprise, and anticipation. In his theory of the wheel of emotions, the secondary emotions that are unique to humans are generated by a mixture of adjacent (primarily dyad), every other (secondarily dyad), and every third (tertiarily dyad) basic emotions. He divided each basic emotion into three levels of gradation, whereby outside emotions become weaker and transit into other emotions more readily. To promote their transition into positive emotions, it is important to weaken the initial intensity of negative emotions.

In terms of schizophrenia, a number of studies have shown that family caregivers were burdened by negative emotions due to the effects of the illness. Emotions expressed by family members are a predictor of poor prognosis for patients with schizophrenia. Expressed emotion (EE) consists of five dimensions: critical comments, hostility, emotional over-involvement (EOI), warmth, and positive remarks (Bebbington & Kuipers, 1994). EE was related to the basic emotions of anger, fear, and

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sadness. However, EE measures the behavior caused by the emotions, not the emotions related to caregiver burden themselves (Shiraishi, Watanabe, Katsuki, Sakaguchi, & Akechi, 2019). Of the secondary emotions, guilt and shame play a role in understanding family caregivers' behavior toward their relatives with the illness. Guilt arises when individuals attribute a negative experience to their own behavior, but shame is felt by attributing the experience to the whole self (Tangney & Fischer, 1995). In caregiving, EOI was associated with guilt and shame, although critical comments were only associated with shame. The association of EOI with shame resulted in more maladaptive behavior of family members (Cherry, Taylor, Brown, Rigby, & Sellwood, 2017). A structure equation model suggests that the overall state of the mental health of family members could be proportionally explained in terms of the emotions related to caregiving (Shiraishi et al., 2019). However, there has been a lack of studies on the proportion of their emotions that are negative and positive. The possible reasons for the lack of studies are that single qualitative studies cannot examine the entire range of emotions range experienced by family members and no measures exist to assess the emotions related to caregiving themselves (Vella & Pai, 2013).

Moreover, few studies have examined the positive aspects of caregiving in schizophrenia (Kulhara, Kate, Grover, & Nehra, 2012). Szmukler et al. (1996) conceptualized two benefits of caring for a patient with the illness: rewarding personal experiences and positive aspects of the relationship with the patient. In fact, positive emotions in caregiving have been investigated mainly in the field of geriatric disorders. Regarding caregiver gain, researchers emphasized subjective feelings expressed as enjoyment, gratification, or satisfaction (Cohen, Gold, Shulman, & Zucchero, 2010; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Motenko, 1989). Caregivers' experience of these emotions is explained by how they perceive their relationships with care recipients (Kramer, 1997; Lawton et al., 1989; Tarlow et al., 2004) and appraise their own self-efficacy or competence (Fortinsky, Kercher, & Burant, 2002; Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002; Vernooij-Dassen et al., 1999). Recent qualitative and quantitative reviews (Lloyd, Patterson, & Muers, 2016; Yu, Cheng, & Wang, 2018) demonstrated the caregiving benefits of relationship maturation and mastery development. From a different cognitive perspective, Farran, Miller, Kaufman, Donner, and Fogg (1999) identified the meanings that individuals attach to caregiving, which were proposed to undergo three stages of development: difficult aspects of caregiving, provisional (day-to-day) meaning, and ultimate (philosophical/religious/spiritual) meaning.

The current study aimed to explore the proportion of negative and positive emotions within the effects of schizophrenia on family caregivers. The meaning of the emotional content was also described regarding each effect of the psychotic disorder.

Method

This study was based on the results of a previous systematic review and qualitative synthesis (Shiraishi & Reilly, 2019), which is summarized here to provide context for this study. The aim of the previous study was to formulate an overall understanding of how caring for a relative with schizophrenia impacted his/her family members. The impacts were defined as the effects of the illness on the positive and negative emotions of family caregivers. The two independent reviewers conducted the following procedures. A literature search yielded 1355 records using five electronic databases: Ovid MEDLINE, Ovid Embase, EBSCOhost CINAHL, EBSCOhost PsycINFO, and Web of Science. The removal of duplicates reduced the sum to 864 records. After title and abstract screening, 46 articles were assessed for eligibility. As a result, 23 articles were included in the synthesis, the process of which extracted 474 findings as being the smallest unit of structure from the 23 qualitative studies. Regarding the defined impacts, the qualitative findings were abstracted into the following themes: uncertainty and unpredictability, loss of expectation of life and health, lack of personal and social resources, difficulty in understanding, stigma and heredity, family disruption, conflict in interpersonal relationships, and the meaningful aspects of caregiving. Centering the positive impacts among the dominant negative impacts, the themes were conceptualized according to the Mandara model, which indicated the way people reached a state of enlightenment in continuous caregiving.

Content Analysis

A benchmark review was conducted through a content analysis of the included studies. Analytical procedures were divided into the extraction of emotions, the coding of the extracted emotions, and the quantification and textualization of the coded emotions. The two reviewers independently examined 474 findings to determine whether each finding had emotional meaning and the types of emotions it involved. The extracted emotions were then coded according to the theory of the wheel of emotions (Plutchik, 1980). The wheel of emotions comprised eight basic emotions (i.e., joy, sadness, trust, disgust, fear, anger, surprise, and anticipation), primary dyads (i.e., love, submission, alarm, disappointment, remorse, contempt, aggression, and optimism), secondary dyads (i.e., guilt, curiosity, despair, revulsion, envy, cynicism, pride, and fatalism), and tertiary dyads (i.e., delight, sentimentality, shame, outrage, pessimism, morbidity, dominance, and anxiety). When the findings showed higher or lower levels of intensity for the basic emotions, they were coded at a basic level of the eight emotions. The first reviewer's results were cross-checked against those of the second reviewer. The reviewers resolved disagreements via weekly debate during research

meetings. Subsequently, the coding was analyzed quantitatively and the number of findings that involved each emotion was calculated as the proportion of the total number of findings for each effect of schizophrenia on family caregivers. To describe the qualitative content, the first reviewer synthesized the findings textually, and the second reviewer critically revised the text several times until they reached a consensus regarding the representation of the involved emotions for each effect of the psychotic disorder.

The Characteristics of the Included Studies

Table 1 shows the characteristics of the 23 studies included in the content analysis. The population of caregivers included 277 participants in the identified qualitative studies (173 women and 104 men). The average number of study participants was 12, and the sample sizes ranged from 5 to 52. The participants in eight studies were from a mixture of different types of family caregivers (Gater et al., 2014; Huang, Hung, Sun, Lin, & Chen, 2009; Ip & Mackenzie, 1998; Mhaule & Ntswane-Lebang, 2009; Mizuno, Takataya, Kamizawa, Sakai, & Yamazaki, 2013; Molefi & Swartz, 2011; Saunders, 2013; Sethabouppha & Kane, 2005). Parents alone were included in four studies (Landon, Pike, Diesfeld, & Shepherd, 2016; McAuliffe, O'Connor, & Meagher, 2014; Pejler, 2001; Tuck, du Mont, Evans, & Shupe, 1997), but the number of participating mothers was 2.6 times higher than that of fathers (21 vs. 8). In five studies, all participants were mothers ($n = 17$) (Rungreangkulkij & Chesla, 2001; Ryan, 1993) or fathers ($n = 25$) (Howard, 1998; Nystrom & Svensson, 2004; Wiens & Daniluk, 2009). In addition, 46 siblings participated exclusively in four studies (Barnable, Gaudine, Bennett, & Meadus, 2006; Gerace, Camilleri, & Ayres, 1993; Stalberg, Ekerwald, & Hultman, 2004; Yang, Hsieh, Lee, & Chen, 2016). Further, although spouses participated in only two studies (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004; Mizuno, Iwasaki, & Sakai, 2011), these studies included 24 wives and 60 husbands.

Results

Quantitative Content

The percentages and proportions of the emotions regarding the effects of schizophrenia on family caregivers are displayed in Table 2 and Fig. 1, respectively.

Qualitative Content

Uncertainty and Unpredictability The caregivers were worried about what would happen to their ill relatives if they died or lost their ability to provide care in the future. Anxiety in

American and Taiwanese parents was common when their ill children had trouble independently managing their daily lives; these parents grasped the incurability of schizophrenia and insufficiency of social resources (Huang et al., 2009; Tuck et al., 1997). Similarly, siblings in the Canadian and Taiwanese studies (Barnable et al., 2006; Yang et al., 2016) were worried about who would assume the caregiving role after their parents' death and did not want to burden their own children with caregiving duties.

The caregivers were fearful of the unpredictable behavior that accompanied the illness. The negative impact of caregiving on their emotions was likened to riding a roller coaster in the American study (Gater et al., 2014) and living on top of a volcano in the Canadian study (Ryan, 1993). Both violence and self-harm evoked a feeling of fear. Landon et al. (2016) quoted the lament of one mother who feared her son's suicidal behavior, "Just talking him down all the time I think was the hard part [tearful]. So it was a very dark, dark time... then there was a stage where two of us did a suicide watch."

The uncertain course of schizophrenia contributed to caregiver ambivalence. Although some parents in the Japanese and Canadian studies (Mizuno et al., 2013; Ryan, 1993) had resigned themselves to the fact that their children would perpetually live with the illness, the unpredictability of an individual disease course meant they were hopeful that recovery would enable better future lives for their ill children. However, hopelessness often accompanied this feeling because parents were likely to witness their children's relapse and deterioration (Tuck et al., 1997).

Loss of Expectations of Life and Health Feelings of sadness and grief were conspicuous among caregivers who had lost their relatives' former selves, and consequently, hope for their relatives' futures. Considering their children's conditions before the illness, some parents in the Western studies (McAuliffe et al., 2014; Tuck et al., 1997; Wiens & Daniluk, 2009) did not expect them to become mentally disabled. Other parents in the Western studies (Ryan, 1993; Wiens & Daniluk, 2009) had abandoned their dreams for their children, who had lost the potential to achieve life goals such as marriage.

The caregivers' social lives were restricted by their ill relatives' condition and their resultant anxiety. The severely disabling nature of the illness made some caregivers feel that they needed to remain near their ill relatives (Gater et al., 2014). Other caregivers experienced fewer opportunities to socialize inside and outside the home because they felt fear and shame regarding others' reactions to people with the condition (Gater et al., 2014; Ip & Mackenzie, 1998; Mhaule & Ntswane-Lebang, 2009). This social isolation intensified their feelings of sadness (Huang et al., 2009). In addition, caregivers lost the time they could otherwise have spent pursuing their own interests. The ability to have a private life was viewed as a right that the ill relative had taken away, which evoked feelings of

Table 1 Characteristics of the Studies Included in the Qualitative Analyses

Study	Setting	Caregivers and care recipients	Methodology	Data collection method
Gerace et al. (1993)	United States	Siblings ($n = 14$) and ill siblings ($n = 14$)	Qualitative case study design	Audiotaped semi-structured interviews
Tuck et al. (1997)	United States	Parents ($n = 9$) and adult children	Phenomenology	Audiotaped interviews
Howard (1998)	United States	Fathers ($n = 12$) and adult children	Descriptive design	Taped interviews with research memos and literature
Saunders (2013)	United States	Family caregivers ($n = 10$) and care recipients	Qualitative exploratory design	Audio-recorded interviews with field notes and journaling
Gater et al. (2014)	United States	Family caregivers ($n = 19$) and patients ($n = 19$)	Grounded theory	Audio-taped face-to-face semi-structured interviews
Ryan (1993)	Canada	Mothers ($n = 5$) and adult children ($n = 5$)	Ethnography	Tape-recorded Ethnographic interviews
Barnable et al. (2006)	Canada	Siblings ($n = 6$) and ill siblings	Hermeneutic phenomenology	Audiotaped semi-structured interviews
Wiens and Daniluk (2009)	Canada	Fathers ($n = 6$) and adult children ($n = 6$)	Phenomenology	Audio-taped interviews with process notes
Mizuno et al. (2011)	Japan	Husbands ($n = 12$) and wives ($n = 12$)	Descriptive design	Tape-recorded face-to-face semistructured interviews
Mizuno et al. (2013)	Japan	Family caregivers ($n = 11$) and patients ($n = 14$)	Descriptive exploratory design	Digitally-recorded focus group interviews
Huang et al. (2009)	Taiwan	Family caregivers ($n = 10$) and adult children ($n = 10$)	Phenomenology	Tape-recorded face-to-face interviews with field notes
Yang et al. (2016)	Taiwan	Siblings ($n = 10$) and inpatients	Descriptive design	Audio-recorded semistructured individual interviews
Rungreangkulkij and Chesla (2001)	Thailand	Mothers ($n = 12$) and adult children ($n = 12$)	Interpretive phenomenology	Audiotaped interviews
Sethabouppha and Kane (2005)	Thailand	Family caregivers ($n = 15$) and adult children ($n = 15$)	Phenomenology	Tape-recorded interviews with notes and journaling
Ip and Mackenzie (1998)	China (Hong Kong)	Family caregivers ($n = 8$) and outpatients	Descriptive design	Audiotaped semi-structured interviews
Pejlert (2001)	Sweden	Parents ($n = 8$) and patients ($n = 6$)	Phenomenological hermeneutics	Audio-taped narrative interviews
Nystrom and Svensson (2004)	Sweden	Fathers ($n = 7$) and adult children	Hermeneutics	Audiotaped one-to-one interviews
Stalberg et al. (2004)	Sweden	Siblings ($n = 16$) and patients ($n = 14$)	Grounded theory	Audiotaped semi-structured interviews
Jungbauer et al. (2004)	Germany	Spouses ($n = 52$) and patients	Grounded theory	Tape-recorded narrative interviews with contact protocols
McAuliffe et al. (2014)	Ireland	Parents ($n = 6$) and adult children ($n = 6$)	Descriptive qualitative design	Tape-recorded semi-structured interviews
Mhaule and Ntswane-Lebang (2009)	South Africa	Family caregivers ($n = 12$) and outpatients	Phenomenology	Audiotaped individual interviews with field notes
Molefi and Swartz (2011)	South Africa	Family caregivers ($n = 11$) and patients	Qualitative exploratory design	Digitally-recorded face-to-face semi-structured interviews
Landon et al. (2016)	New Zealand	Parents ($n = 6$) and adult children	Descriptive design	Digitally-recorded semi-structured interviews

anger and distress. However, mothers in the Canadian study (Ryan, 1993) felt simultaneous guilt because these feelings conflicted with their parental responsibility.

The studies also demonstrated that caregiving exerted a strong effect on the caregivers' health. These effects ranged from physical strain to mental stress. The North American studies (Barnable et al., 2006; Gater et al., 2014) indicated that caregivers often felt tired, exhausted, and worn out under

physical stress, which worsened pre-existing somatic disorders. In some instances, psychological stress reached the severity of a depressive disorder (McAuliffe et al., 2014).

Lack of Personal and Social Resources Knowledge deficit and undeveloped skills were noticeable in the earlier stage of caregiving. When an affected individual manifested the disease symptoms, his/her family members' feelings of fear and

Table 2 Percentages of findings with emotional meanings within the total number of findings for each effect of schizophrenia on family caregivers

Negative effects total	Uncertainty and unpredictability	Loss of expectation of life and health	Lack of personal and social resources	Difficulty in understanding	Stigma and heredity	Family disruption	Conflict in interpersonal relationships	Meaningful aspects of caregiving
64.2% (n = 163/254)	81.3% (n = 26/33)	86.8% (n = 33/38)	56.6% (n = 30/53)	47.6% (n = 10/21)	73.1% (n = 19/26)	69.2% (n = 18/26)	47.4% (n = 27/57)	61.5% (n = 32/52)

helplessness were heightened by the fact that they did not have sufficient knowledge or skills to control their relatives’ pathological behavior (Barnable et al., 2006; Mizuno et al., 2013; Sethabouppha & Kane, 2005). The Asian study (Huang et al., 2009) suggested that the extent of insufficient knowledge and skills was influenced by the availability of social resources to help them care for their ill relatives. The caregivers tended to be annoyed by the inadequacy of the resources available from the mental health field (Landon et al., 2016; Mhaule & Ntswane-Lebang, 2009; Wiens & Daniluk, 2009).

Finances were perceived as stressful, problematic, and the cause of difficulties. Moreover, caregiving interfered with family members’ jobs and contributed to financial strain (Gater et al., 2014; Huang et al., 2009). As many parents reached old age, another contributor to their stress was their retirement (Huang et al., 2009; Landon et al., 2016). When a family member had to resign from work to provide care, this could increase other family members’ workloads, which was described in the American study (Gater et al., 2014) as follows, “I cannot go to work. So financially, it has put a burden [on us]. My husband had to take a—second job because—to—to supplement my income.”

Difficulty in Understanding The caregivers attributed their relatives’ illness to biological and psychosocial causes. Genetic predisposition was a major concern, but caregivers were inclined to favor psychosocial causes such as childrearing or family dysfunction (Gerace et al., 1993; Mizuno et al., 2013; Pejler, 2001; Saunders, 2013). For mothers who blamed themselves for giving birth to and/or parenting the child, there seemed to be no way for them to avoid their sense of guilt. Similarly, siblings felt guilty when they believed they were part of the family environment that contributed to the development of the illness (Barnable et al., 2006; Stalberg et al., 2004).

The illness was also attributed to supernatural forces and karma. African caregivers, who did not doubt the practice of witchcraft offered by a person who held a grudge, were likely to blame schizophrenia on someone close to them (Mhaule & Ntswane-Lebang, 2009; Molefi & Swartz, 2011). Karma emerged as a way for family members to be punished for their bad deeds in the past or a previous life. Guilt was most common among caregivers who believed that the illness was a punishment from God or their ancestors for their poor conduct in the past (Mhaule & Ntswane-Lebang, 2009; Rungreangkulkij & Chesla, 2001).

The caregivers experienced difficulty in understanding what schizophrenia meant. Some participants in the Chinese study (Ip & Mackenzie, 1998) could not identify which behaviors were symptoms of schizophrenia, and some in the American study (Gater et al., 2014) could not imagine how their ill relatives thought and felt within their experience of the illness. Due to a lack of understanding, siblings in the

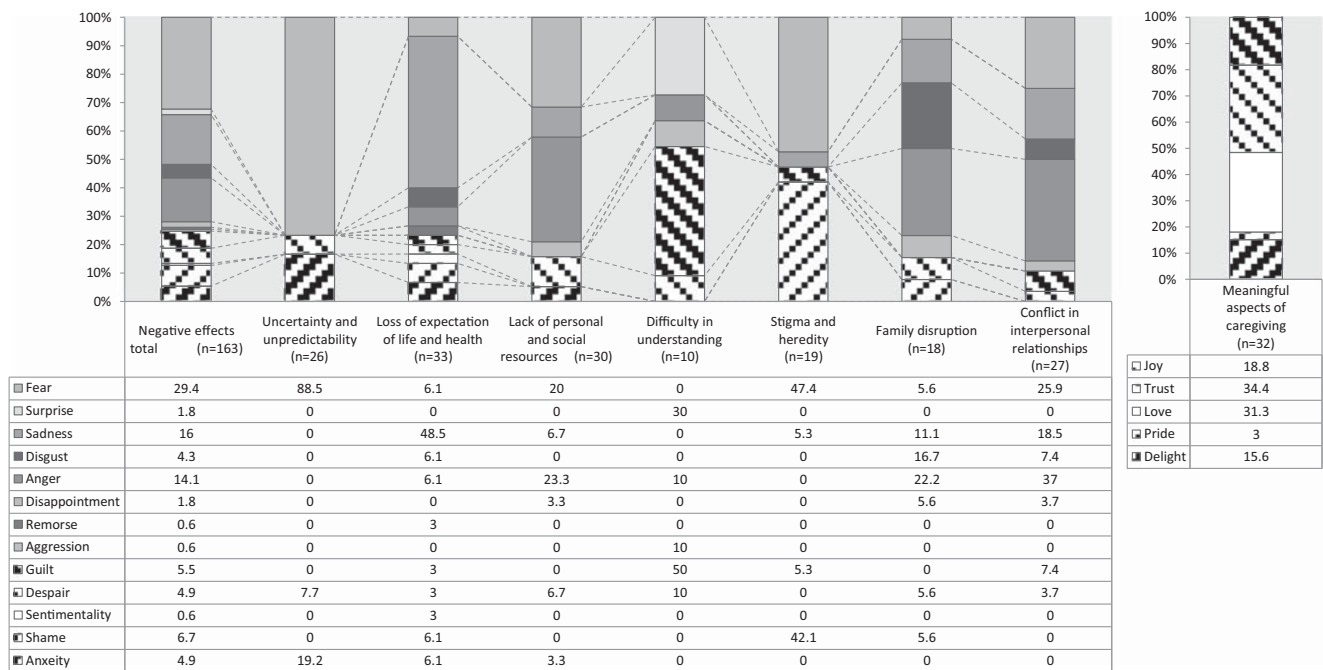


Fig. 1 Proportions of the emotions experienced in family caregivers for each effect of schizophrenia

Canadian study (Barnable et al., 2006) felt annoyed and helpless following their relatives' diagnoses. Family members in Mizuno et al.'s (Mizuno et al., 2013) study gradually developed an understanding of the illness, but one Japanese mother continued to feel that schizophrenia was confusing, even years after the diagnosis.

Stigma and Heredity The caregivers were likely to be worried and ashamed by the stigma of mental illness. In the Asian and African studies (Ip & Mackenzie, 1998; Mhaule & Ntswane-Lebang, 2009; Sethabouppha & Kane, 2005), they suspected gossip, whereby neighbors talked about their relatives' illness behind their backs. A primary reason for the suspicion was their previous experience of their ill relatives' bizarre behavior (Mhaule & Ntswane-Lebang, 2009; Pejler, 2001). A Swedish study involving siblings (Stalberg et al., 2004) showed that they hesitated to be open about their relatives' illness because of their fear of being labeled abnormal. Because of stigmatization, the participants tended to isolate themselves from society, which could increase their risk of developing depression (Huang et al., 2009).

Siblings feared the possibility that they would develop the illness themselves or pass it on to their children. Stalberg et al. (2004) quoted the words of a Swedish sibling, whose two relatives were mentally disordered, as follows, "Yes, about this thing being hereditary—I had understood that. I got worried about my kids." One parental concern about their healthy children was whether this fear would prevent them from getting married or having their own children (Mizuno et al., 2013). The fathers in the Canadian study (Wiens & Daniluk, 2009) blamed themselves for genetic components in their family histories of mental illness. In addition, some siblings

in the Swedish study (Stalberg et al., 2004) were aware of their parents' feelings of self-blame.

Family Disruption Family life, as a whole, can be disrupted by the ill person's pathology. In Western studies, disorganized behavior made it difficult for family members to live together because some were upset by what they saw and heard (Howard, 1998; Landon et al., 2016). In addition, aggressive behavior distanced nonprimary caregivers from their ill relatives. The continuous disruption could result in the family splitting, and primary caregivers stated that they felt isolated in the New Zealand study (Landon et al., 2016). In particular, when an ill child behaved violently toward his/her mother, the other children felt angry and restless as observed in the Japanese and Swedish studies (Mizuno et al., 2013; Stalberg et al., 2004).

Family disruption includes dysfunction in the family members' roles. Mothers and fathers lost self-confidence in their roles as parents (Nystrom & Svensson, 2004; Tuck et al., 1997). In a case in which an affected child could not function as an independent adult, the loss was expressed by a mother in Ryan's study (Ryan, 1993) as, "It's like having a child, a permanent child that never grows up... so you feel that you're doing a lifetime of mothering." Further, one wife in Jungbauer et al.'s study (Jungbauer et al., 2004) felt that her additional responsibility was similar to having a third child, described as follows, "I don't want to assume the role of the mother, but sometimes I have to. Then sometimes, this is too much for me." When the caregiver role suddenly emerged as the family members' responsibility, disagreement about how to bear this new responsibility caused friction among the family (Barnable et al., 2006).

Conflict in Interpersonal Relationships Conflict was reported in relationships between parents, siblings, or spouses and their ill relatives. The parents in the Swedish study (Pejlert, 2001) were concerned about their children's daily lives, including issues such as spending too much time in bed and gaining weight continuously. Some mothers in the Thai study (Rungreangkulkij & Chesla, 2001) hid their feelings of anger, enduring their ill children's behavior and limitations to avoid expressing negative emotion and worsening their children's condition. Envy and guilt were characteristic emotions in the relationships between siblings. Stalberg et al.'s study (Stalberg et al., 2004) showed that envy could have been mutual, but unaffected siblings felt guilty about being healthy while their ill relatives faced schizophrenia. In terms of spouses, the German study (Jungbauer et al., 2004) examined these relationships and showed that the main reason for conflict was that ill spouses failed to meet their partner's expectations of marital life, including sexual relations.

Conflict was also observed in relationships between parents, siblings, spouses, and other relatives. For example, marital relationships between parents could be negatively affected by mothers' tendency to be more involved than fathers in caregiving (Nystrom & Svensson, 2004). McAuliffe et al. (2014) quoted an Irish mother who lamented, "It's very bad for a marriage—for a mother to have so much hardship, so much worry, because you have no time to spend with your husband." In addition, parental involvement in caregiving could exert a negative effect on the relationship between parents and their other children. The parents in the American study (Gater et al., 2014) often reported that they did not look after their other children as much as they should have. Further, having a relative with schizophrenia could exert an adverse effect on the relationship between his/her family caregivers and members of the extended family. The African study (Mhaule & Ntswane-Lebang, 2009) showed that family caregivers were isolated and felt excluded by their extended families.

Moreover, caregivers were irritated with mental health professionals, from whom they expected help for not only patients but also their family members. Studies conducted in Western countries (Barnable et al., 2006; Landon et al., 2016; Pejlert, 2001; Saunders, 2013; Wiens & Daniluk, 2009) showed that parents and siblings felt excluded by professionals who did not genuinely listen to what they reported. However, some parents were not inclined to question their uncooperative attitudes, out of fear of being viewed as problematic. The Swedish and Canadian studies (Barnable et al., 2006; Pejlert, 2001) suggested that their sense of being excluded resulted from confidentiality in clinical practice. Landon et al. (2016) quoted a mother who was not provided with personal information about her son, as follows, "The thing that made me angry, well not... yeah, angry, I suppose, or upset, was that the Mental Health or the Privacy Act had stopped any communication with me whatsoever."

The Meaningful Aspects of Caregiving Three domains of appraisal were conceptualized from the subthemes in which the family caregivers felt the positive emotions of trust, love, joy, delight, and pride. First, caregivers' relationships matured through favorable appraisal of interpersonal relationships, which comprised family solidarity, affection, and compassion. Experiencing difficulties made the family members feel that caring for their ill relatives had united and solidified their families (Barnable et al., 2006; Wiens & Daniluk, 2009). Affection and love facilitated the acceptance of having a relative with schizophrenia and caring for him/her without reward, particularly for parents (McAuliffe et al., 2014; Sethabouppha & Kane, 2005; Wiens & Daniluk, 2009). Compassion was observed not only within families but also between caregivers and people outside the family (Mizuno et al., 2011; Sethabouppha & Kane, 2005; Wiens & Daniluk, 2009). Second, caregivers' mastery was developed by the favorable appraisal of inner strength that comprised gaining knowledge and skills, self-confidence, and personal growth. They understood the importance of gaining knowledge and skills. Moreover, the more knowledge and skills they had acquired, the less threatened they felt by an illness that could ruin their relationships (Jungbauer et al., 2004). Through such caregiving experiences, they became confident and aware of their strengths (McAuliffe et al., 2014; Wiens & Daniluk, 2009) and felt they had grown as people, because they generalized their caregiving capacity and had new perspectives on life (Nystrom & Svensson, 2004; Wiens & Daniluk, 2009). Third, the maturation of relationships and development of mastery were considered to have been enhanced when family members appraised mutual behaviors favorably through affirmation (Huang et al., 2009; McAuliffe et al., 2014), admiration (Gerace et al., 1993; Wiens & Daniluk, 2009), and appreciation (Landon et al., 2016; Wiens & Daniluk, 2009).

Discussion

The results of the quantitative and qualitative analyses suggest the meaning of the negative and positive emotions experienced by family caregivers of individuals with schizophrenia. The uncertain and heritable features of schizophrenia prompted the fear and anxiety affecting family caregivers. The loss of the caregivers' expectations about their lives and health was predominately related to depressive feelings. Caregivers were also likely to blame themselves as a cause of the relative's illness. These negative emotions can turn caregivers' attention to the future and the past and distract them from living in the present. Schizophrenia also disrupted family lives, roles, and relationships, which tended to confuse family caregivers and result in feelings of fear, anger, and sadness. Shame resulted from the stigma of mental illness

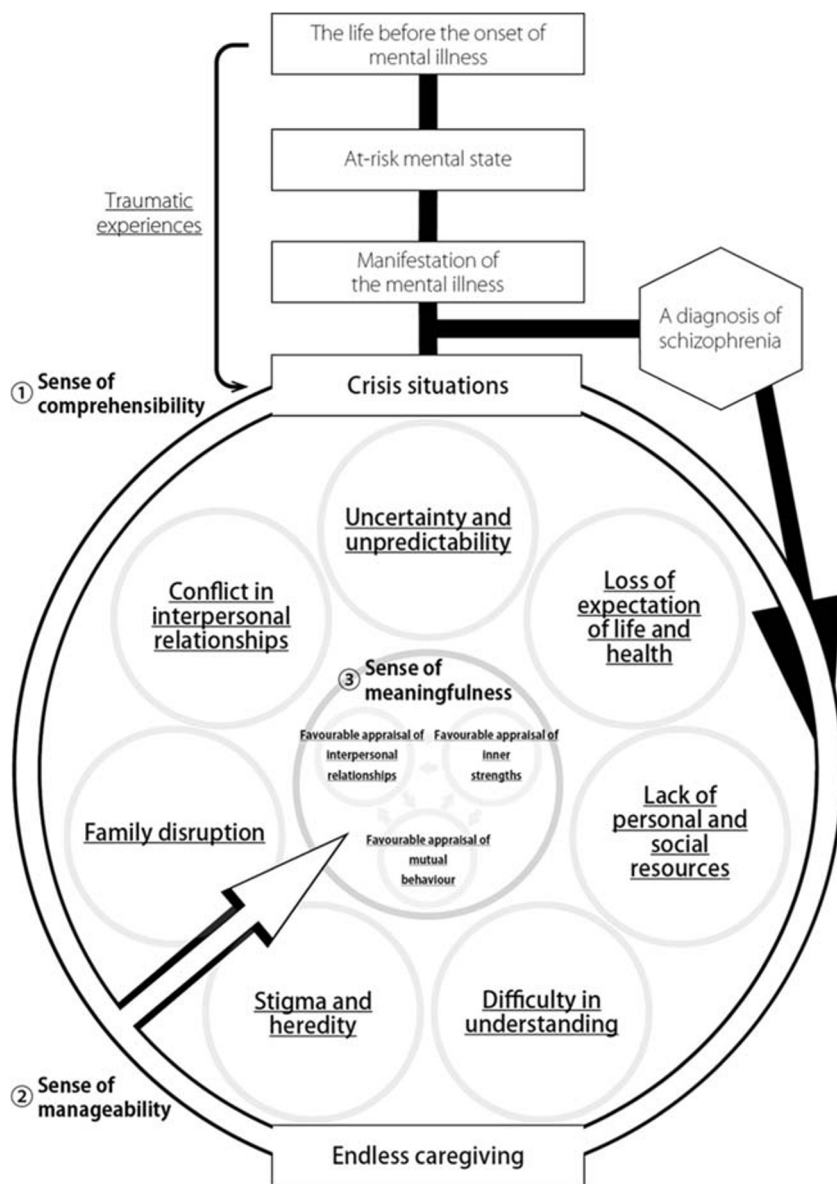
and made the caregivers being inclined to isolate themselves from the community. The apprehension and annoyance caused by a lack of personal resources were enhanced by the conflicts with social resources and health professionals. Both negative emotions made it difficult for the caregivers to see themselves as a member of the society and the professionals as allies in facing the difficulties associated with caregiving. Conversely, trust, joy, and love appeared to cultivate their feelings of belonging to the family, the community, and society.

Community and social support affected how family members felt about the burden of caring for a relative with schizophrenia. The family burden was associated with negative emotions related to caregiving, including worry, anger, sadness, and guilt (Kuipers, Onwumere, & Bebbington, 2010). Emotional rather than practical support was related to a

reduction in the burden of care in schizophrenia cases (Grandon, Jenaro, & Lemos, 2008). Feelings of being unsupported might emerge from caregivers’ perception of themselves as excluded from health services. Possible reasons for the feelings were that family members were prone to hide their emotions, and their caregiving roles were taken for granted by health professionals (Gray, Robinson, Seddon, & Roberts, 2010). However, the professionals could notice and appreciate the loving and compassionate relationships among family members, despite the difficult circumstances (Gray, Robinson, Seddon, & Roberts, 2009). Understanding the emotions’ meaning in care experiences could allow professionals to provide more effective support for family members.

Integrating the concept of the sense of coherence (SOC), the Mandara model suggests a way to support family caregivers (Fig. 2). The SOC involves health factors commonly

Fig. 2 The Mandara model of caregiving process, interpreted via the sense of coherence. *Note.* The original figure was obtained from Shiraishi and Reilly (2019)



found within a group of people exposed to extreme trauma who maintained their well-being and succeeded in coping with stress (Antonovsky, 1979, 1987). The sense of comprehensibility is the first subordinate concept of the SOC, in which one's current and future situations can be understood and predicted to some extent. To strengthen this sense, health professionals should be able to surmise and reflect family caregivers' negative emotions, because an empathetic attitude helps to build collaborative relationships in facing difficult realities. The sense of manageability is the second subordinate concept, in which issues can be managed and resolved. To reinforce this concept, professionals should enable the caregivers to cope with the difficulties by utilizing personal and social resources with a respect for their own decision-making process. The sense of meaningfulness is the third concept, in which daily activities, including coping with stress, inspire one to do something worthwhile and feel that life is worth living. To foster this sense, the caregivers should be empowered empathetically, collaboratively, and continuously by the professionals who provide affirmation, admiration, and appreciation for the family relationships based on trust.

Limitations of the Research

This study was subject to some limitations in its representativeness. For example, the included studies were conducted in Western, Asian, and African countries. Not including studies in other regions reduced the generalizability of the findings to caregivers with different cultural backgrounds, but some studies in similar fields were conducted in Middle Eastern countries (Tamizi et al., 2020; von Kardorff, Soltaninejad, Kamali, & Eslami Shahrabaki, 2016). In addition, the characteristics of the study participants could have differed from those of general caregivers and care recipients. Approximately 26% of the studies included had recruited participants from support groups or family associations, in which members might have held more positive attitudes to the difficult circumstances relative to those of others (Chen & Greenberg, 2004). Less background information was available for care recipients than caregivers, which increased the difficulty in confirming whether their clinical histories included schizophrenia. Further, in the coding process, the reviewers could have misunderstood the exact meaning of the qualitative findings in the included studies. This possible failure was potentially due to variance in the richness of the participants' descriptions and the unavailability of the verbatim transcripts for in-depth interviews.

Conclusions

Our analyses and descriptions enhance the current understanding of the emotions experienced in family caregiving for schizophrenia. Each effect of the psychotic disorder is

interpreted in terms of a pattern of negative and positive emotions and the meaning of both emotions. The pattern and meaning of the emotions provide information that will help health professionals empathize with caregivers and support them in facing difficult challenges. Such emotion-based support could allow family members to find positive meaning in their care experiences, whereby they could develop feelings of trust, joy, and love. Further research is required to examine the effects of intervention based on the Mandara model of caregiving process and the related emotions. This study contributes to a deeper understanding of why some people achieve a state of enlightenment in continuous caregiving.

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Code Availability Not applicable.

Ethical Approval Statement Not applicable: this research does not involve human participants and/or animals.

Informed Consent Not applicable: informed consent from human participants was obtained in included studies in accordance with the ethical standards of the institutional research committee.

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