Positive aspects of caregiving in schizophrenia: A review

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Abstract

Schizophrenia is a severe mental illness which is associated with significant consequences for both the patients and their relatives. Due to chronicity of the illness, the relatives of patients of schizophrenia have to bear the main brunt of the illness. Studies across the world have evaluated various aspects of caregiving and caregivers such as burden, coping, quality of life, social support, expressed emotions, and psychological morbidity. In general the research has looked at caregiving as a negative phenomenon, however, now it is increasingly recognised that caregiving is not only associated with negative consequences only, also experience subjective gains and satisfaction. This review focus on the conceptual issues, instruments available to assess the positive aspects of caregiving and the various correlates of positive aspects of caregiving reported in relation to schizophrenia. The positive aspect of caregiving has been variously measured as positive caregiving experience, caregiving satisfaction, caregiving gains and finding meaning through caregiving scale and positive aspects of caregiving experience. Studies suggests that caregivers of patients with schizophrenia and psychotic disorders experience caregiving gains (in the form of becoming more sensitive to persons with disabilities, clarity about their priorities in life and a greater sense of inner strength), experience good aspects of relationship with the patient, do have personal positive experiences. Some of the studies suggest that those who experience greater negative caregiving experience also do experience positive caregiving experience.

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INTRODUCTION

Early onset of the illness, persistence of symptoms in the long run and chronic relapsing course of schizophrenia has far-reaching consequences for both the patients with schizophrenia and their relatives. Due to the illness, the patients may have diminished capacity for social relationships, they may not be able to take care of themselves and their day-to-day needs, face reduced employment opportunities and if employed, may be less productive. The illness thus hampers independent living and may lessen life satisfaction. Family members of patients with schizophrenia are often confronted with uncertainty about the
course of the illness, lack of reciprocity in relationship with the patient and the trepidation of unpredictable symptoms. They also have to meet the cost of care (direct, indirect and intangible) besides accepting patient’s lost potential and impending unemployment or reduced prospects of employability of the patient. No wonder the caring relatives often experience grief and have to cope with stigma and social isolation, which leaves them with a feeling of shame, embarrassment or guilt. Thus, the illness leads to considerable emotional, financial and real-world demands on those close to the sufferer, typically the parents or the spouse. Moreover, studies have shown that caregiving frequently leads to mental morbidity, neglect of health of self and higher risk of mortality. Caregivers also experience gradual burnout while caring for their loved ones. Parents, spouses, and siblings are often unable to deal with their own individual or family developmental needs because the focus is so often on the care of the relative with schizophrenia. Many studies across the world have evaluated various aspects of caregiving and caregivers such as burden, coping, quality of life, social support, expressed emotions, psychological morbidity et al. Till recently, caregiving was thought to be a negative phenomenon, however, now it is increasingly recognised that caregiving is not only associated with negative consequences only, but the caregivers also experience subjective gains and satisfaction. In this article we focus on the conceptual issues and current understanding of positive aspects of caregiving and review research regarding these in relation to schizophrenia.

**CONCEPT OF POSITIVE ASPECTS OF CAREGIVING**

Positive caregiving experience is a subjective event, as such no standard formal definition of this is available. Various authors have understood positive caregiving in terms of caregiver gains, satisfaction and caregiving experience. Many researchers have assessed positive caregiving experience in the domains of duty/obligation, companionship, fulfillment, reward, quality of life, enjoyment, meaning, etc. Caregiver esteem, uplifts of caregiving, finding or making meaning through caregiving and caregiver appraisal has extensively reviewed negative and positive aspects of caregiving. Next we will briefly discuss the positive aspects of caregiving.

Kramer gave the concept of caregiver gain after a critical review of literature on positive aspects of caregiving, and described it as “the extent to which the caregiving role is appraised to enhance an individual’s life space and be enriching”. It may include any positive yield to the caregiver as a result of the caregiving experience. Kramer proposed a model of caregiver adaptation in which “appraisal of role gain” is an intervening process through which background and contextual variables act to influence well being. It is suggested that caregiving gains may be related to the resources like coping and social support that the caregiver possesses. Kramer also tried to conceptualize gain as both an event-specific and a role related construct. Event-specific gain includes responses to specific caregiving tasks, and role-specific gain pertains to more general appraisals of the caregiving role. Other authors have defined caregiver gains as “the caregiver’s perceived personal growth and enhanced interpersonal relationships”.

The caregiving benefits/gains described in the literature include feeling more useful, feeling needed, learning new skills, and adding meaning to one’s sense of self, gaining a sense of fulfillment for meeting a duty/obligation and enjoyment derived from caregiving itself or from companionship with the care recipient.

Caregiver satisfaction is one of the most commonly used terms with respect to positive aspects of caregiving. Initially caregiver satisfaction was defined as “the benefits occurring to the caregiver through his or her own efforts”. Later, the same group of authors defined caregiver satisfactions as, “subjectively perceived gains from desirable aspects of or positive affective returns from caregiving” or “the result of caregiving experiences that give life a positive flavor”. It has been shown that caregiver satisfaction may be related to positive affect and to burden.

Nolan et al. described 3 dimensions of “caregiving satisfaction”-satisfaction derived mainly from the interpersonal dynamics between carer and the cared for person, satisfaction derived from intrapersonal or intrapsychic orientation of the carer and satisfactions derived mainly from a desire to promote a positive or avoid a negative outcome for the care recipient.

Another positive aspect of caregiving cited in the literature includes “Uplift”. Kinney et al. defined uplift as an event that makes one feel good, makes one joyful, or makes one glad or satisfied. Uplifts are also understood as “daily events that evoke feelings of joy, gladness, or satisfaction”. It is hypothesized that uplifts buffer the effects of hassles. Studies have shown that when uplifts outweighed hassles, caregivers reported less distress.

The construct “finding meaning through caregiving” is another aspect of positive caregiving and was initially identified in a preliminary qualitative study of family caregivers of persons with dementia in which the caregivers responded to a series of open-ended questions, and the researchers identified 6 major themes based on the qualitative analyses of the responses. Later, the authors developed a 135-item “Finding Meaning Through Caregiving Scale (FMTCS)” and tested its psychometric properties. They identified 3 subscales: Loss/Powerlessness, which identifies difficult aspects of caregiving; Provisional Meaning, which identifies how caregivers find day-
to-day meaning; and Ultimate Meaning, which identifies philosophical/religious/spiritual attributions associated with the experience of caregiving.

Caregiver esteem is another facet of positive caregiving which has caught the attention of researchers and is assumed to be the extent to which performing caregiving tasks enhance the caregiver’s self-esteem.

Some studies have also demarcated positive aspects of caregiving as improved relationships, feeling appreciated, pleasure, and prevention of further deterioration⁴⁻⁸. Other positive aspects which have been studied include positive caregiving experience which has two components, positive personal outcomes and good aspects of the relationship with the patient⁹.

### MEASURING POSITIVE ASPECTS OF CAREGIVING

The positive caregiving experience, as measured by Experience of Caregiving Inventory (ECI) of Szmukler et al⁹ is based on the concept of caregiving appraisal, which involves both positive and negative facets of the caregiving experience. The ECI has eight subscales measuring the negative experiences while two subscales quantify the positive caregiving experience-positive personal outcomes and good aspects of the relationship with the patient. Studies based on ECI have shown positive correlation between positive and negative caregiving experience. However, this scale does not ascertain many other positive aspects of caregiving. Caregiver appraisal scale was designed to measure caregiver satisfaction and it chiefly assesses caregiver satisfaction in relation to caring for elderly family members. It includes a subscale on caregiver satisfaction, wherein caregiver satisfaction is measured by questions such as “patient’s pleasure over something gives you pleasure, you are happy knowing that patients is feeling better for the family, helping patient makes you feel closer to him/her, the patient shows appreciation for what you do for him/her”, etc. Other components of caregiving assessed by Caregiver appraisal scale are caregiver ideology and caregiving mastery⁹⁻¹⁰.

Pearlin⁹ designed a 10 item Caregiving Gains Scale to assess caregiving gain which was later adapted by researchers and has been used to study caregiving gains in caregivers of mentally ill subjects²⁴⁻²⁶. “FMTCS” was developed by Farran et al²⁷, which is a 7-point Likert-type 43 item questionnaire. Psychometric evaluation of scale identified 3 subscales: Loss/Powerlessness identifying difficult aspects of caregiving; Provisional Meaning, which identifies how caregivers find day-to-day meaning; and Ultimate Meaning, which labels philosophical/religious/spiritual attributions associated with the experience of caregiving. Of these various scales, ECI has commonly been used to study the positive aspects of caregiving in relation to schizophrenia.

We recently developed a Scale for Positive Aspects of Caregiving Experience (SPACE). For developing this scale, available scales (ECI⁹, Caregiver Appraisal Scale⁸, Adapted Caregiver Gains scale²⁷, Positive Aspects of Caregiving²⁷) assessing some aspect of positive caregiving were reviewed. Items were taken from these scales and common items were condensed and accordingly incorporated in SPACE. Then the scale was evaluated in the caregivers of patients with schizophrenia and was found to have good internal consistency; test-retest reliability, cross language reliability, split half reliability and face validity. Principle Component Analysis yielded a factor structure comprising four factors. The factor so obtained also had good test-retest reliability. The 4 factor domains of positive caregiving identified are caregiving personal gains, motivation for caregiving role, caregiver satisfaction and self-esteem and social aspect of caring²⁸.

### POSITIVE ASPECTS OF CAREGIVING IN APPRAISAL PARADIGM

Caregiver appraisal is a neutral term in that it can indicate positive, neutral, or negative feelings about the caregiving situation. It is based on the transactional perspective wherein it is understood as a transaction between the person and the environment³⁰. To “appraise” is understood as to “set a value on”, “estimate the amount of”, or “evaluate the worth, significance, or status of” something²ⁱ. Therefore, caregiver appraisal refers to the process by which a caregiver estimates the amount or significance of caregiving, in which he takes into consideration both the nature of the stressor and his or her resources to cope with these. Hence, caregiving appraisal may be positive, negative, or neutral³⁰ and consists of subjective cognitive and affective appraisals of the potential stressor and the efficacy of one’s coping efforts³⁰. So “appraisal of caregiving” is understood as a construct existing in the “stress-appraisal-coping” framework, and suggests that the experience of caregiving results from an interaction between the relative’s illness and factors in the carer’s external and internal world. According to this, patient’s illness, associated behaviors, disabilities and the perceived disruptions of the carers’ life are appraised as stressors by the carers. The carer’s personality, quality of family relationships and degree of social support are considered as the mediating factors in caregiver’s appraisal of the stress²³⁻³⁶. A caregiver may appraise the whole caregiving experience as positive, negative or both depending on the interaction between the various variables and the outcome is understood in the form of psychological morbidity. However, it is possible that not all caregivers will experience psychological morbidity; hence, it would be prudent to consider other outcome measures like quality of life.

Thus, while evaluating the positive aspects of caregiving, it would be worthwhile to evaluate the caregivers coping ability, social support, psychological morbidity, quality of life, perceived burden and level of caregiving involvement and caregiving consequences.
POSITIVE ASPECTS OF CAREGIVING IN PSYCHOTIC DISORDERS

Few studies have evaluated positive aspects of caregiving in patients with schizophrenia, schizophrenia spectrum disorders and patients with psychosis. Chen and Greenberg\[20\] assessed 560 caregivers of patients with schizophrenia spectrum disorders through telephonic interview on Caregiving Gains Scale developed by Pearlman\[31\]. They found that although the experiences of gains were quite prevalent, not all respondents had positive experiences with all aspects of gains. Almost 70% of the caregivers reported that they had become more sensitive to persons with disabilities. More than 50% reported that caring for their relative helped them significantly in clarifying their priorities in life and generated a greater sense of inner strength. Tarriere et al\[35\] compared the experience of caregiving in patients with psychosis in 95 Italian patients and their caregivers with 69 British patients and caregivers on the ECI. They found no significant difference with regards to the positive caregiver appraisal between the two samples. However, they found that the caregivers in both the samples valued the “good aspects of relationship” more than “the personal positive experiences” in the positive domains of the caregiving. Addington et al\[40\] followed up 185 caregivers of patients with 1st episode psychosis and evaluated them on the ECI at baseline and each year of follow-up, with 91 caregivers continuing in the study after the 3 year period. They found that these caregivers prized the positive personal experiences more than the good aspects of the relationship during each assessment of the caregiver during the study period. Treasure et al\[50\] compared 68 caregivers of patients diagnosed to have psychosis with 71 caregivers of patients with anorexia nervosa and found that the caregivers of patients with psychosis valued the positive personal experiences more than the good aspects of the relationship with their patient while the opposite was true for the caregivers of anorexia nervosa. In addition, caregivers of patients with psychosis experienced a lower total positive score on ECI. Aggarwal et al\[40\] evaluated 50 caregivers of patients with schizophrenia using the ECI. They found that caregivers valued the domain of good aspects of relationship more than the personal positive experiences domain. We compared caregiving experience of caregivers of patients with schizophrenia with caregiving experience of caregivers of patients with bipolar disorder using ECI and found that caregivers of patients with schizophrenia had overall more positive and negative appraisal of caregiving experience while caring for their ill relatives. However, there was a significant positive correlation between the negative and positive caregiving experience score for both schizophrenia and bipolar groups\[41\].

RELATIONSHIP BETWEEN POSITIVE ASPECTS OF CAREGIVING AND BURDEN

Relationship between positive and negative aspects of caregiving has been studied using ECI or use of burden scale and scales assessing some positive aspect of caregiving. Hsiao et al\[42\] reported that family caregivers with a more positive interpretation of family caregiving reported lower levels of family caregiver burden. In another study, Pickett et al\[29\] reported that parent’s positive appraisals of their relationships with their mentally ill adult child were significantly related to decreased levels of caregiver burden. Studies which have assessed caregiving experience using ECI suggests that caregivers who appraise the caregiving experience more negatively also appraised the same more positively\[38,40,46\]. However, some of the studies have not reported any relationship between positive and negative caregiving experience as assessed by ECI\[39\].

CORRELATES OF POSITIVE ASPECTS OF CAREGIVING IN PSYCHOTIC DISORDERS

While the positive aspects of caregiving have been recognized, the importance of recognizing factors associated with positive aspects of caregiving is being increasingly acknowledged. Current research has begun to focus on the correlates of positive aspects of caregiving. Although research in this sphere is still in a nascent stage, some studies have shown that positive aspects of caregiving are influenced by socio-demographic, clinical and psychological variables.

Studies show more educated caregivers report higher levels of positive personal experiences, higher level of perception of good aspects of relationship\[24,46\] and overall positive caregiving experience\[24,46\]. More positive caregiving experiences are noted when the patients are females\[24,46\] when the caregivers are men of an older age group and when caregivers have low family incomes\[47\]. Some studies have also shown that caregivers of patients who were young\[42\] and unemployed\[24,46\] reported less positive experiences. However other investigations do not show significant relationship between the caregiving appraisals and age, gender and employment of the caregiver\[41\].

The relationship between caregiving and the psychopathology is rather inconsistent. One study reported that the caregivers of patients with higher positive symptoms of schizophrenia reported more positive caregiving experience\[46\]. Another study showed that higher scores on “avolition-apathy” domain of negative symptoms as measured by the Scale for Assessment of Negative Symptoms was associated with lower positive appraisals\[24\]. Some studies do not show significant relationship between relatives’ appraisal of caregiving and patients’ symptomatology\[24,46\]. Better patient functioning is related to greater positive appraisal of caregiving according to some investigators\[24,46\]. One study reported higher positive caregiving experience when there was a family history of psychosis\[41\]. Onwumere et al\[38\] reported that positive caregiving appraisals were more common in caregivers of patients with longer illness duration.

With regards to the level of involvement of caregiver in the patients care, it has been shown that caregivers
report more positive experience when the caregiver had shared a better previous and current relationship with the care recipient, had fewer daily hours of responsibility as a caregiver, and when they had become caregivers by their own initiatives\[47.\]. A study assessing the caregiver’s gains among older parents of adults with serious mental illness reported that parents who provided more help to their children with mental illness reported more gains than parents who were less involved in helping their children. This study also found that the amount of help the parent provided correlated significantly with the amount of assistance the child provided to the parent, suggesting reciprocity in the relationship\[53.\].

Many psychological variables like coping strategies, religious practices and perceived social support have been shown to have some influence on the positive caregiving experience. Studies involving coping skills show that the caregivers who use problem focused coping strategies and seek social support as a coping strategy experience a higher level of positive personal caregiving experiences\[49.\]. A study from India, found that less use of denial and greater use of problem solving coping was associated with greater caregiver well being\[50.\]. There is no consensus with regard to use of religious coping strategies with some studies showing that religious coping strategies frame the caregiving experience in a positive manner\[31.\], while other studies report that religious coping had little influence on the caregiver well being outcomes\[52.\]. There are very few studies that have evaluated the relationship of religious practices with positive aspects of caregiving. One study reported that religiosity was associated with better self-esteem and self-care and less of depression among the family caregivers\[33.\]. Social support also plays an important role in positive aspects of caregiving as significant positive associations between the experience of caregiving benefits/gains and family socio-emotional support\[48.\] have been reported. Onwumere et al\[51.\] studied caregivers of patients with nonaffective psychosis and reported that positive caregiving appraisal correlated with higher levels of perceived caregiver and patient control of the illness. Predominately illness beliefs were significant predictors of caregiving appraisal and distress rather than illness length, caregiver ethnicity, or type of caregiver. Aschbrenner et al\[50.\] assessed the caregivers gains among older parents of adults with serious mental illness and reported that support from an adult child with serious mental illness, presence of more number of confidants and being member of the parent’s support group were the variables which were positively and significantly correlated with personal gains for the parent. Another study which evaluated reciprocal exchange between a mentally ill and other family members, reported that amount of support patients give to their parents and siblings is strongly associated with how much support they receive from family members\[54.\].

**CONCLUSION**

In current schizophrenia literature, research involving buried experience by caregivers grossly overshadows studies regarding positive aspects of caregiving. However, this scenario is changing and positive aspects of caregiving are drawing more investigative attention. Studies from various cultures have shown that perception of family burden varies across different contexts and that these variations are only partially explained by patients, carers and relationship features and hence it would be inappropriate to compare or generalize the findings of studies from one culture to another. Similarly, it is expected that the positive aspects of caregiving will also be influenced by the cultural factors. Studying positive aspects of caregiving will help the clinicians in identifying and promoting factors that contribute to positive caregiving, improve the mental health of the caregiver and thereby enhance the overall care of their patients in a particular cultural setting.

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