

# Schizophrenia: Impact on Family Dynamics

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**Abstract** In many societies, family members are now the primary caregivers of mental health patients, taking on responsibilities traditionally under the purview of hospitals and medical professionals. The impact of this shift on the family is high, having both an emotional and economic toll. The aim of this paper is to review the main changes that occur in family dynamics for patients with schizophrenia. The article addresses three central themes: (i) changes in the family at the onset of the disorder, (ii) consequences for family members because of their caregiver role, and (iii) family interventions aimed at improving the complex dynamics within the family.

After analyzing and discussing these themes, it is observed that despite advances in the field, the viability of taking care of a patient with schizophrenia by the family remains a challenge. Improving care will require commitments from the family, the mental health service system, and local and national governments for greater investments to improve the quality of life of society in general and individuals with schizophrenia in particular.

**Keywords** Schizophrenia · Family · Impact · Dynamic · Care

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## Introduction

### The Effect of Schizophrenia on Families at the Beginning of the Disorder

Schizophrenia is a mental health disorder that is associated with high illness costs in a number of different respects. Although some will fully recover, a considerable portion of the patients suffers from long-term disability, which often includes irregular episodes [1]. Families play key roles in the early stages of the disease when help is first being sought. In addition, families provide long-term care and continued support for people experiencing schizophrenia with most of patients continuing or returning to live with relatives [2]. The caregiver role is often difficult and exerts a significant impact on the carer's own mental health [3]. Over a third of family caregivers reported a high level of perceived burden and difficulties coping with their child's or spouse's illness [4–9].

Soon after diagnosis, carers experience a range of different negative emotions as they attempt to deal with the diagnosis of a family member [10, 11]. However, some family members fare better than others do in terms of their wellbeing in the carer role. This response depends on many different factors.

One of the most important aspects in the caregiver response is the cognitive appraisal processes related to the illness. That is, how they interpret and make sense of the illness and the extent to which they feel they are capable of coping with the problems [12]. A negative illness perception on the part of relatives has been linked to heightened patient distress, which also predicts distress many months later, indicating the value of assessing and understanding the caregiver's adaptation to the disease [13–16]. Another aspect that increases distress in relatives is the age of the patient at diagnosis and of the onset of service use, especially if the family assessment of the costs of the illness is low [17, 18].

The factors that affect the relatives' responses to the illness are not only associated with family processes but are also related to the help-seeking experience. Relatives can feel excluded from the doctor–patient consultation process and experience negative attitudes directed toward them by health professionals. Mental health professionals have been criticized for under-appreciating the importance of conveying a schizophrenia diagnosis clearly and without bias, in particular of being judgmental instead of supportive and empathetic to the patient and the relatives [19]. This is supported by research showing that patients preferred knowing that they had schizophrenia rather than not knowing what was wrong with them and suffering from uncertainty [20, 21]. Clear communication of the relevant information about their disease helps the patients make informed decisions about their own healthcare and adjust to their illness [20]. In addition, positive early interactions and clear communication with healthcare providers may

also reduce the level of distress experienced by family members [22]. It is recommended that contact with caregivers should be planned and included early in diagnostic discussions to prevent the expression of negative attitudes against the patients and to improve the outcomes of treatment [19].

The help-seeking experience can also produce contradictory emotions, such as fear, guilt, and relief, in family members, which may in turn affect their own relationships and self-confidence. This can be both stressful and traumatic for the family [22], particularly shortly after diagnosis, when interactions with healthcare providers are often tinged with despair. Whereas some individuals describe their interactions with mental health professionals as positive and the providers as compassionate toward the patient and family [23], some family members feel dismissed and provided with insufficient information. Thus, during this early period following initial diagnosis, the relationships between individual family members and healthcare providers are of central importance, potentially setting the stage for the overall experience and perception of the caregiver burden.

Additional factors that affect both the caregiver's and patient's wellbeing are the interactions within and between families. Notably, different family environments affect the coping strategies used by families during acute schizophrenic episodes. These can predict the recurrence of episodes in the future and the overall course and outcome of the disorder. Familial attitudes toward the patient and their effect on the patient's risk of relapse have been studied under the expressed emotion (EE) framework, with high levels of EE prognostic of worsening symptoms and future psychiatric episodes [4, 24]. High levels of EE within a family may in part be a reflection of the overall caregiver's burden and the manifestations of symptoms in the patients [25]. However, high-EE families of schizophrenia patients show a number of maladaptive behaviors. These include the frequent internalization of criticisms and/or inadequate expression of emotions and thoughts in response to criticisms from both patient and caregiver, which can increase the risk for relapse. In addition, EE correlates with the level of family cohesion and flexibility and with family burden, which appears to determine whether the household can change from a high-EE to low-EE family [21, 25].

From this analysis, we conclude that the impact of schizophrenia on the family is complex. Factors contributing to this complexity are the lack of provision of sufficient information about the diagnosis by healthcare providers, the family's reactions to the diagnosis and the patient, poor bidirectional communication between the family and patient, and ineffective coping strategies within the family environment that can affect the level of symptoms and increase the occurrence of relapses.

## Consequences for Family Members Because of Their Role of Care

Role theory states that having a patient with schizophrenia disrupts normal family dynamics, with every family member affected in some manner and many caregivers' roles even being annulled [26–30]. Caring effects refers to the impact of providing care on the family in terms of individual, social, and economic changes [31]. Mental and physical health are significantly affected [32], with caregivers of patients of schizophrenia reporting worse health status than non-caregivers or caregivers of patients with other disorders, such as Alzheimer's disease or epilepsy [33•]. Families of psychiatric patients are affected by their role as caregivers on many levels, including lowering their quality of life and their ability to provide care [34–41]. Thus, the quality of life is defined by the level of caregiver's health and wellbeing relative to different dimensions of their lives [42]. One of the biggest factors influencing the caregiver's psychosocial burden is the course of the disorder. The positive symptoms of the schizophrenia patient have a clear impact; however, negative symptoms, such as impaired working memory and executive functioning, can also decrease caregivers' quality of life [30, 43–46].

Low caregiver quality of life often manifests as physical illness, the loss of vitality, and depressive and anxiety disorders [46–50]. These symptoms can be triggered by the unrelenting concerns of a caregiver, including being adequately competent to advise and assist the patient to adjust [30], managing patient's behavior and work and social interactions [51], and concerns about the patient's future [30, 40]. These factors affect the level of psychological distress experienced by the caregiver and can affect the overall caregiver experience [52•, 53–56].

Another significant deterioration experienced by the family (reported by up to one-third of family members) is the disconnection with other family members due to the existence of a mental disorder within the family [57–59]. This is also related to the stigma experienced by the family members [52•, 60–62] and to the low levels of social support that they usually receive [4, 43, 63]. Financial issues can also have negative consequences on family dynamics. These arise in part due to the limited capacity of the patient to work. In addition, the time burden on the caregiver required for patient care frequently prevents the caregiver from taking on full-time work as well [47].

Although most of the consequences of caring for a patient with schizophrenia tend to be negative, in recent years, some carers have begun to identify more positive and beneficial aspects of this role (e.g., feelings of been more sensitive, useful, and needed and a higher sense of strength) [33•, 64, 65]. Other changes deriving from the establishment of the diagnosis can have positive effects on the members of the family. These can include improvement of the family dynamics, such

as having more social support, having a job outside the home (for both patient and caregivers), and being treated through family interventions.

Assessing the impact of caregiving on families of schizophrenia patients is an important consideration not only for the wellbeing of the family but also for the health of the patients. Healthcare professionals need to recognize this issue and integrate such assessments into their treatment decisions, working more directly with the family to improve outcomes for the patient. Family experiences should be comprehensively assessed either on the individual level via interviews or on the group level (e.g., by using a focus group of caregivers). Standardized questionnaires, which have been validated with varying evidence [4, 46, 66, 67], may be of use in both clinical practice and research, leading to easier, objective, and reproducible assessments. However, the critical question for clinicians and researchers is which tool in their practice is the most relevant for this context. Several factors should be considered in making this choice. First, the questionnaire design should be a key factor. Because of discrepancies between families and experts' perspectives [68], a questionnaire based on the subjects' perceptions should be preferred. However, few of the existing questionnaires are based on the caregivers' and families' views. Second, the performance of the questionnaire should be validated in terms of its effectiveness [69], taking into consideration psychometric properties such as internal consistency, construct validity, and sensitivity to change. However, this information is not available for several commonly used instruments, and there is a particular lack of information regarding the sensitivity to change. This is a major problem for clinicians, especially when evaluating interventions such as psychoeducational or therapeutic programs. Third, the language in which questionnaires were developed is a factor. The direct translation of a questionnaire may be inadequate due to some concepts, such as quality of life and burden of care, being affected by cultural background. Such translations must be subjected to strict transcultural validation protocols, making it preferential in most cases to use questionnaires within their country of origin [12].

Finally, another existing assessment, the dyadic approach, could be of the utmost interest for clinicians but has been rarely explored in research. This approach globally incorporates the interactions between the patient and family to design interventions that address the needs of both groups. This approach has been used effectively in dementia patients to address both their mental and physical health [70, 71]. However, this approach has not yet been used to test interventions on the schizophrenia patient-caregiver dyad, and the impact of family interventions on the burden and quality of life of caregivers is currently unknown.

## Family Interventions

Family interventions (FI) for schizophrenia consist of a combination of psychotherapeutic strategies aimed at developing a working relationship between the family and the medical team to support patient recovery [72]. FIs are recommended as evidence-based interventions and treatment of choice by some of the most important worldwide mental health institutions, including the American Psychiatric Association (APA) [73] and the National Institute for Health and Clinical Excellence (NICE) [74, 75].

Well-established research findings show that family interventions for people with schizophrenia spectrum disorders can prevent relapse and hospitalizations, increase medication adherence, maintain satisfactory family interactions, and have a positive impact on both patients' and relatives' quality of life [76–78]. On top of these positive achievements, recent clinical trials have also shown that FIs can improve participants' cognitive dysfunction [79] and relatives' guilt induction, dominance, and empathy [80]. In terms of maintenance of these results, longitudinal studies such as the one conducted by Ran and colleagues confirm that the effects are enduring [81].

No gold standard approach has been established. FIs usually include psychoeducation, stress management, emotional processing, assertive communication, cognitive reappraisal, and structured problem solving [31]. FIs are always conducted by mental health providers; however, they can differ in their theoretical basis, modality, and length. Advanced research in this field aims to investigate the mechanisms of change for these interventions. A recent systematic review conducted by Grácio, Gonçalves-Pereira, and Leff (2015) aimed to tease out the therapeutic process involved in FIs [82•]. These authors carefully analyzed the results of 22 relevant studies in order to discover the key elements of FIs, concluding that, following efficacy parameters, there are three key elements for a successful process: therapeutic alliance, education, and training in coping skills. When considering the participants' and relatives' points of view, the key elements are reduced to education, human connection (that can be also understood as therapeutic alliance), and reframing.

Format delivery and duration have been also targeted as potential mediators of change. According to Sin and colleagues, there are four main categories of format delivery: individual (therapist seeing a relative of the whole family); groups (relatives attend sessions together); mixed (a combination of the two previous options); or other (any format that differs from the previous ones). Overall, duration of the intervention ranges between 4 and 36 weeks, inclusive of 6 to 12 weekly or biweekly sessions [83]. Unfortunately, findings supporting an ideal and successful design for the type of delivery and duration of the program are inconclusive, and further meta-analyses are needed.

Finally, it is important to highlight that FIs are well accepted by both participants and relatives and that they express high levels of satisfaction when ending the programs [83, 84, 85•]. By using qualitative methods, it has been shown that participants and relatives commonly consider FIs a space “to listen to and share experiences” (a safe space) [83], to improve communication between family members [86], to better understand the illness and its impact on the individual, and to learn problem solving skills [87].

However, two big challenges remain that are related to FIs: the professional's training and the implementation of the intervention. Overcoming these two related challenges will have a tremendous impact on the access of patients and relatives to FIs. Staff training is required in order to disseminate the approach in conjunction with mental health services. However, some barriers that prevent clinicians and researchers from accessing training and implementing FIs exist. Notably, access to clinical supervision that provides specific training on adequate skills and the confidence to deal with family problems are some of the most common training needs reported by staff [76]. Furthermore, protected time and support from the management system and organization are prerequisites for clinicians to go in depth into FI training and to incorporate it into their daily work routine. In this regard, Eassom and colleagues claim that successful implementation of FIs critically depends on a change in organizational culture regarding the role of the family in the treatment process (e.g., prioritizing working with families) [76]. Discrete evidence-based FIs can be a solution because they do not require therapists trained to an expert level. Instead, evidence-based FIs can be delivered by frontline mental health professionals, being less dependent upon a redesign of services to undertake the work [88].

Online interventions may offer another potential solution to those looking for support and seeking information about schizophrenia. Technological advances and digital media are creating a revolution in healthcare that is also affecting the implementation and dissemination of FIs. Interestingly, Rotondi and colleagues designed a web-based psychoeducational intervention for people with schizophrenia and their supporters (the “schizophrenia online access to resources” website or SOAR) [89, 90•]. People who participated in the pilot study and were given access to the website showed a greater reduction of symptoms as well as a better understanding of their illness. Furthermore, their relatives/supporters also showed a better understanding of the prognosis, in comparison to their counterparts receiving only routine care. Furthermore, the authors found a positive relationship between symptom reduction and the frequency of access to the online resources [89]. These authors are currently conducting a randomized controlled trial that aims to compare the SOAR to in-person, multi-family, psychoeducational treatment, and to treatment as usual (ClinicalTrials.gov Identifier: NCT02032680). Results of this trial are estimated to be



available in 2018. Focusing on first-episode psychosis, Sin and colleagues has also designed an online multicomponent psychoeducational intervention for siblings of individuals with a first-episode psychosis [91] (<http://siblingspsychosis.org/>, ISRCTN01416694). This innovative intervention combines two major components (psychoeducation and peer support) and has been built with the input of an expert advisory group that comprises siblings, parents, service users, mental health clinicians, youth organization personnel, and e-learning IT experts. Results of this rigorous clinical trial are expected to be available at the end of 2016.

## Conclusion

Several decades have passed since the deinstitutionalization of mental health patients. With the noblest intentions, this process also highlighted the lack of resources that families and community supporters had to help people experiencing schizophrenia. Major steps have been made in the provision of mental healthcare since this decision was made back in the 1950s. However, the establishment of a diagnosis of schizophrenia spectrum disorder can still have a negative effect on the individual and on his/her family and friends, which implies that the diagnosis requires the readjustment of the whole family to the new situation.

Specific changes in the dynamics, areas of conflict, needs, maladaptive behaviors (e.g., EE), and protective factors in the patient's family must be assessed by clinicians as soon as the diagnosis is communicated. In addition, FIs should be offered regularly to families since they have been shown to be effective in improving symptomatology, illness awareness, and satisfaction levels in both patients and relatives. If this process is done properly, a successful recovery process and an improvement in the quality of life is much more likely to happen.

Politicians, clinicians, researchers, and community workers are fully aware that families are in need of greater support and resources to be able to cope with the consequences of schizophrenia. Staff training and implementation of FIs can have a tremendous impact on the lives of patients and family. These actions, therefore, should be implemented and offered to service users and their relatives in every single outpatient mental health service around the world.

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## Compliance with Ethical Standards

**Conflict of Interest** The authors declare that they have no conflict of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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