

## Educational Needs of Families of Patients with Schizophrenia: A Literature Review

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### Abstract

**Introduction:** Families of patients with schizophrenia face serious challenges due to clinical heterogeneity and multiplicity of symptoms and their management. Investigating educational needs of families can improve the quality of life for both patients and families. In this study, special educational needs of these families were investigated through a systematic review of previous studies.

**Methods:** This systematic review was conducted in Persian data bases such as Iranmedex, Iran doc, SID and English data bases of Cochran, PubMed, Science Direct, and Medline. Also, the used English keywords were educational needs, family, schizophrenia and their equivalents in Persian language. A total of 15740 articles were found. Finally by considering the inclusion criteria, 16 articles were selected and evaluated to answer the study's questions.

**Results:** The analysis of the data extracted from the 16 selected papers for the research question implies that the needs of families of patients with schizophrenia include six dimensions: social interactions, support resources, access to the unknown items in the disease, coping and stress management, stigma and improving the quality of life.

**Conclusion:** The results suggest that proper understanding of the problems in families of patients with schizophrenia not only helps the families of patients, but also teaches the professionals involved with them to change their attitude towards educational planning. Furthermore, any planning without considering the role of family is doomed to fail.

**Keywords:** Educational Needs, Family, Schizophrenia

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### 1. Introduction

Psychologists consider human-beings as a biopsychosocial unit that is always in a state of dynamic adaptive change with psychological disorders able to disrupt this adaptive state (1,2). Among psychotic disorders, schizophrenia is a disruptive disorder that affects about 1% of the population. This disorder is one of the most debilitating mental disorders, and severely affects personal, social and professional functions (3). Because of its multidimensional nature and the influence it exerts on various aspects of personal and family life, this disorder leads to huge conflicts and serious damages to the family structure and order (4). Schizophrenia is stressful for both the patient and their family; studies show that between 50% and 80% of patients with this disorder either live with their family or are regularly in touch with their family members (5,6). To remain a part of the family, these patients require financial and psychological support from their families; the quality of relationships between the patient and the family members can therefore have a major effect on the outcomes of the disease (5). The family and

caregivers of these patients face major challenges with clinical heterogeneity, multiplicity of symptoms and the manner of dealing with these symptoms, and, due to the multidimensional nature of the disease, also have to bear numerous financial, physical and mental costs.

Furthermore, the pressures imposed by the disease destroy family interactions and lead to indifference, financial problems arising from the patient's costs of care and disability, social isolation arising from withdrawal from social activities given the great amount of time spent caring for the patient and a lower quality of life overall for these families (2,7-10). Examining the specific educational needs of these families can have a major effect on their knowledge and attitude, and consequently, on the way they care for and interact with these patients, and ultimately lead to an improved quality of life for the patients and their families (11). Many studies have been conducted on the importance of family support and education in improving schizophrenic patient care. Results of a study conducted in China to assess the educational needs of families of patients with schizophrenia emphasized the importance of



assessing the specific needs of the families of these patients (2). Other studies address the problems and sufferings of families of schizophrenic patients (8,12,13). Review of literature on the topic indicates that, over the past 15 years, the importance of the family and their educational needs have been emphasized as the primary source of long-term care of schizophrenic patients (1,4,8,9). Dixon argues, "Assessing the needs of family members is the pillar of relation and cooperation between the family and the therapist. Because family members tend to blame themselves for the illness of one member, and as the diseased member has lost his/her previous level of performance, they chronically experience mild to severe grief, and it is under such circumstances that they feel helpless and need to gain more knowledge" (14). The therapist's intervention for making an assessment of and a proper response to these needs reduces their confusion, isolation and mental pressures (4,9,15). Families of schizophrenic patients require special training to reduce their amount of stress caused by patient care and need to be provided with the essential information; families cannot be an effective member of the therapy team unless they have a proper understanding of the problems associated with the disease, and without this information, family members will remain dependent on the therapists forever, unable to properly monitor and control the patient's behavior. Without training, they cannot guide the patient toward greater self-sufficiency, which is the ultimate end in the treatment of these patients.

## 2. Methods

In this review study, the required information was sought, retrieved, evaluated, integrated, and systematized based on the study's questions, including:

- What are the dimensions of the educational needs of families of schizophrenic patients, and what areas should this education stress?

The search strategy involved the identification of relevant articles published between 2007 and 2014. An electronic search was therefore carried out in Persian and English using the keywords "educational needs, family and schizophrenia", in both languages in databases including PubMed, Medline, ScienceDirect, Cochrane, Irandoc, Iranmedex and SID. The study's inclusion criteria were:

- Articles written in English.
- Experimental study with an emphasis on schizophrenic patient care.
- Studies assessing the role of families in the care of these patients.
- Studies addressing the training and educational needs of families of these patients.

All articles and studies written and conducted before 2007, anonymous articles, book reviews, recommendations, letters to editors, history articles, non-scientific articles, theses and non-English articles were excluded from the study.

To assess the quality of articles collected, various aspects of the articles, particularly their methods and the reliability of the data, were reviewed by two of the researchers. In the end, 16 articles were qualified for entering the study (Figure 1). The full text of these articles were abstracted, synthesized and then classified according to the central question of the study.

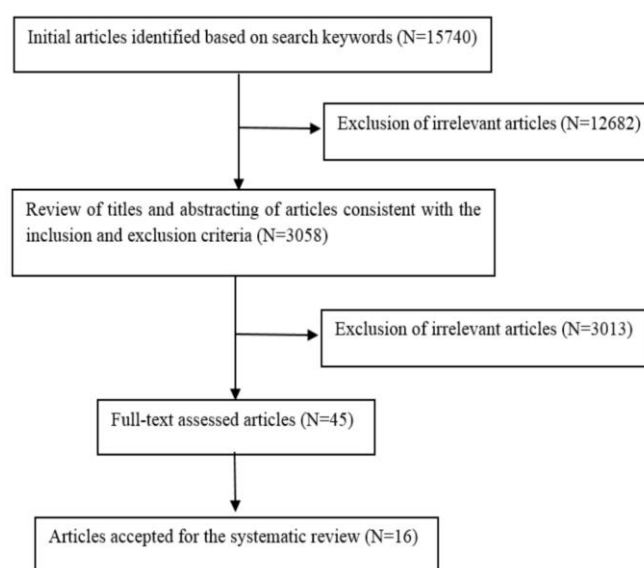


Figure 1. Selection of Articles.

## 3. Results

Results obtained from the analysis of the data of the 16 selected articles (Table 1) suggest six dimensions for the needs of families of schizophrenic patients, including social interactions, sources of support, access to knowledge about the unknown aspects of the disease, stress management and coping, stigma and improving the quality of life.

### Social interactions:

This dimension indicates the reduced social interaction of families due to concerns about the unpredictable behaviors of the patient. This issue makes them avoid participating in social activities and thus reduces the family's social roles. In educational planning, the empowerment of family members to play their role in social interactions is considered as an important dimension of their educational needs (7, 8, 12,13).

**Sources of support:**

This dimension suggests the inadequate community support as a reason for the incompatibility of these families. The absolute lack or deficiency of social support for these families leads to unbearable stress and anxiety for them and creates an incompatibility between the family members and also between the family and the community. The families of these patients are in serious need of support and information. Teaching these families how to access psychosocial and financial support is therefore another dimension of their educational needs. Educating and developing support networks for the families reduces the family's anxiety, increases their physical and mental health, improves the mental health indicators "family stress and social acceptability", increases social compatibility and reduces stress, anxiety and depression (9, 12,16).

**Access to knowledge about the unknown aspects of the disease:**

This dimension indicates that the families' lack of knowledge about the nature of the disease, about how it was developed and how it progresses, and what personal and social limitations the patient experiences, its methods of treatment and duration of persisting, make the tensions created in these families escalate. Another dimension of the educational needs of these families that can increase their perception and knowledge is to gain knowledge about the different dimensions of the disease, including its multidimensional nature and the role of genetic, family, environmental, nutritional and other influential factors yet to be proved or rejected. Leading the families to know that treatments could be time-consuming and that drug-therapy can be highly effective in controlling severe symptoms of the disease encourages them to properly follow-up and refrain from self-discontinuation of the drug-therapy and the patient's acceptance (1, 2, 11, 13, 17).

Stress management and coping: This dimension indicates

the fact that the families of patients are faced with challenges in different areas of their lives, including relationships, their own role in the disease of the ill member of their family, the unknown future of the family, the proper manner of expressing feelings and the acceptance of the disease. They also believed themselves to be faced by many dilemmas in life, being unable to choose the right option given their conditions. As a result, the families of patients with schizophrenia have to deal with great amounts of stress and mental pressure. Gaining knowledge of proper stress management and reducing strategies is another educational need for these families (2,5,7,9,18).

**Stigma:**

This major issue indicates a problem that exists in most families with a member who has schizophrenia or any other mental disorder. It is a problem that is the root of many problems associated with the social interactions of the individual and the family, and has caused their isolation, namely, the issue of "being stigmatized as the psychotic person's family". Teaching families how to deal with this issue and improving the perception and attitude of both families and the community toward this disease is another dimension of the educational needs of these families (7,13).

**Improving quality of life:**

Quality of life significantly declines in families of schizophrenic patients. This is firstly due to the mental, physical and financial problems imposed on the family, and secondly, because of the unwillingness of the patient to be employed, which removes them from entertainment and social activities for the benefit of taking care of the patient. Empowering families to learn and apply the various strategies of improving quality of life is therefore another dimension of their educational needs (1, 3, 19, 20).

**Table 1.** Details of reviewed studies conducted on the educational needs of families of schizophrenic patients

Author	Publication Year	Type of Study/ research instrument	Main Findings and Strategies
<b>Khankeh, et al. (1)</b>	2011	Controlled Trial / Demographic Data Questionnaire, Research-Made Questionnaire	Patients with psychotic disorders will greatly benefit from receiving care within the family and it is only under these circumstances that they can have a fulfilling, productive life when provided with the necessary skills and support systems.
<b>Omranifard, et al. (2)</b>	2011	Phenomenological Qualitative /Face to Face Interview	The three main concepts associated with caregivers' educational needs include sociability, reaction to tension, and access to unknown aspects of the disease.
<b>Khodadadi, et al. (3)</b>	2012	Cross-Sectional Descriptive Survey /QOL Questionnaire	Familiarity with methods of improving quality of life is a determining criterion for the impacts of schizophrenia and its treatment on the patient.

<b>Yildiri, et al. (4)</b>	2014	Pretest-Posttest semi-experimental study the Perceived Family Burden Scale (PFBS) , Disease Information Form (DIF) , Self-Efficacy Scale (SES)	A “family-to-family support” education program is effective in reducing the educational needs of the family and caregivers, the costs incurred and the pressures imposed on the family as well as self-efficacy.
<b>Sharif , et al. (5)</b>	2012	Controlled trial / Brief Psychiatric Rating Scale (BPRS)	<p>A short-term psychoeducational program can improve outcomes for the patient and the family.</p> <p>Session 1: Introducing the family to the psychoeducational program, and establishing an honest relationship between the family and the trainer.</p> <p>Session 2: Introduction to schizophrenia, its symptoms and treatment, and its effects on the patient and the family.</p> <p>Session 3: Understanding the effects and side-effects of drugs.</p> <p>Session 4: Introducing the family to recurrence risk factors and preventing the patient's re-hospitalization.</p> <p>Session 5 and 6: Improving communication skills in the family.</p> <p>Session 7: Managing and overcoming symptoms.</p> <p>Session 8: Learning effective ways of expressing feelings.</p> <p>Session 9: Introducing the family to stress management techniques within the family.</p> <p>Session 10: Introducing the family to relaxation techniques.</p>
<b>Booeini , et al. (6)</b>	2013	Analytical and Descriptive /Two-part Researcher-Made Demographic (Patient and Caregivers) Questionnaire	The attitudes of caregivers (the family) can provide the patient with physical and mental comfort. A change of attitude can be brought about through public and family education with an emphasis on home care and through the use of mass media.
<b>Koujalgi , et al. (7)</b>	2013	Cross-Sectional/ Pollack and Perlick Scale, Family Burden Interview Schedule (FBIS)	Families of schizophrenic patients incur huge costs. Greater practical support is therefore required for them, and since, in these families, resettlement of the family system, the roles and the resolutions vary, family members require greater capacity for treatment and crisis management.
<b>Panayiotopoulos, et al. (8)</b>	2013	Controlled trial / the Involvement Evaluation Questionnaire	Families of schizophrenic patients bear huge financial, physical and psychological costs. Families and patients become less involved in social activities due to the symptoms of the disease, which itself gives rise to more stigmatization. The welfare system should therefore provide these patients and their families with more innovative programs.
<b>Loga, et al. (10)</b>	2012	Transversal, randomized, descriptive and comparative Family Quality of Life Survey (FQLS)	The families of patients are faced with several challenges in their access to health care services.
<b>Chien, et al. (11)</b>	2007	Randomized controlled trial /Family Assessment Device, FBIS	Providing psychoeducational interventions and support groups, and emphasizing the special family and cultural needs of the families can improve their psycho-social health and reduce the patients' risk of re-hospitalization.
<b>Galderisi,et al. (12)</b>	2014	Structured Clinical Interview for DSM-IV - Patient version (SCID-I-P)	A major part of schizophrenic patients' daily life, including their independent life and their effective and social activities, is deficient. Though, among the factors at play, psychological cognition is only indirectly related to real life performance, it has the greatest impact of all. Access to disability benefits and access to family and social incentives also have a significant direct relationship with the patients' performance.
<b>Song, et al. (13)</b>	2014	Controlled trial / Recruit	Findings indicate that there are currently only a few courses available in psychoeducation. Patients and their families like to

		interview	obtain more information about the disease. Families and patients have different educational needs. Wrong perceptions of the disease can impede rehabilitation.
<b>Eack , et al. (16)</b>	2007	Clinical Trial /Quality Of Life Interview (QOLI)	The two factors of (1) Social Support and (2) Basic Needs Supply are effective in improving quality of life in the families.
<b>Shimazu, et al. (17)</b>	2011	Randomized controlled trial / Five-Minute Speech Samples	Providing the families with psychoeducation is effective in reducing the patients' risk of re-hospitalization.
<b>Twamley, et al. (19)</b>	2008	Randomized Control Trial(RCT)/Positive and Negative Syndrome Scale, Hamilton Rating Scale for Depression (HAM_D)	Schizophrenic patients are able to work if provided with proper support. Quality of life increases in these patients through the desirable outcomes of being employed.
<b>Lotfi Kashani, et al. (20)</b>	2010	Controlled trial / GHQ-28 Questionare	Providing training in psychoeducation to the family is effective in improving the general health of the family.

#### 4. Discussion

Schizophrenia is one of the most severe mental disorders that negatively affects the patient and their family mentally, physically and socially. In addition, in today's society, taking long-term care of these patients is a responsibility of their families as the first line of care. Due to the families and consequently the society's lack of proper knowledge about the disease and their inadequate skills for overcoming symptoms of the disease and managing crises and the lack of sources of support, schizophrenic patients and their families cannot have a fulfilling, productive life. Due to the society's attitudes toward this disorder and to avoid being stigmatized and feeling ashamed and also since a great amount of their time is spent caring for the patient, families of these patients are isolated and do not participate in social activities (9,21,22).

According to the numerous studies that have examined this disorder and its associated problems, the main issues comprising the educational needs of these families are:

1. Lack of proper perception and understanding of the disease, its treatment and associated problems (1,2,6,13).
2. The physical, mental, and financial costs of the disease, its destructive effects on the family's quality of life and ways to minimize them (4,7,8,20).
3. Educational needs associated with interpersonal and family relationships, adaptive and problem-solving skills (1,5,7,9,20).
4. Establishing a therapeutic relationship and interacting with the patient (1, 5, 8 & 9).
5. Sociability, strategies for coping with stress, learning about the unknown aspects of the disease (2, 7, 9, 15 & 20).

Many studies have emphasized the communication of information and education as the first priority in providing

services to these patients and their families. The following issues are worth noting:

1. A good treatment for schizophrenic patients is combined drug and psycho-social therapies. Drug therapy is the first line of treatment that is highly essential yet inadequate. The main purpose of treatment should be to improve the patient's performance capacity and quality of life, which can be achieved through psycho-social education, and includes Cognitive Behavioral Therapy (CBT), Social Skills Training (SST), Family Therapy (FT), Assertive Community Treatment (ACT), Individual Therapy and Cognitive Rehabilitation Therapy (CRT) (20).
2. Psycho-education is effective in improving the general health of the family (5).
3. The patient's physical and psychological welfare and comfort can be established through changes in the family's attitude brought about by public and family education (6,16).
4. Psychological cognition and access to disability benefits and family and social incentives can be effective in the patients' social activities (12).
5. Psycho-educational interventions, support groups and emphasizing the cultural and special needs of the families can guarantee their psycho-social health and reduce the patients' risk of re-hospitalization (11).
6. The principle of patient care within the family has greatly contributed to the creation of a productive, effective life for the patient and their family (1).
7. Social support and providing basic needs are effective in improving quality of life for the family and the patient (19).
8. The patient and the family's increased knowledge through mass media can effectively help the early diagnosis and treatment of the disease (6).
9. Family-to-family education program is effective in reducing educational needs, costs incurred and

pressures imposed on the families and in making them feel useful (4).

10. Subsidized employment programs contribute to creating a feeling of usefulness for oneself and for the community, increasing self-confidence and increasing family income (18).

11. Psycho-educational interventions have primary and secondary outcomes:

Primary outcomes of psycho-education include the increased capacity of the patient and the family and the reduced recurrence of the disease. Secondary outcomes of psycho-education include improved knowledge and information, better social and public performance, improved mental status, improved quality of life, reduced health costs and better use of services (during hospitalization and after discharge) (14,16).

## Conclusion

Analysis of data obtained from reviewed studies indicates that the needs of families of schizophrenic patients are focused in areas including sociability, stress management, acquiring knowledge about the unknown aspects of the disease, being stigmatized, improving quality of life and the lack of adequate sources of support. Gaining a proper understanding of the problems of families of schizophrenic patients teaches both the families and the professionals involved with these patients to change their attitude toward educational planning. In addition, any planning that fails to take into account the families and the effective roles they play is doomed to failure.

## References

1. Khankeh H, Rahgozar M, Ranjbar M. The effects of nursing discharge plan (post-discharge education and follow-up) on self-care ability in patients with chronic schizophrenia hospitalized in Razi psychiatric Center. *Iranian Journal of Nursing and Midwifery Research*. 2011;16.2:162.
2. Omranifard V, Mehrabi Tayebah Kheirabadi G. educational needs of schizophrenic patients'families. *Journal of Isfahan Medical School*. 2011.
3. Khodadadi N, Baghaie M, Sheikholeslami F, Mahmudi H. Quality of life in schizophrenic patients. *Zahedan Journal of Research in Medical Sciences (tabib-e-shargh)*.2012.
4. Yildirim A, et al. The Effect of Family-to-Family Support Programs Provided for Families of Schizophrenic Patients on Information about Illness, Family Burden and Self-Efficacy. *Turkish Journal of Psychiatry*. 2014; 25.1.
5. Sharif F, Shaygan M, Mani A. Effect of a psycho-educational intervention for family members on caregiver burdens and psychiatric symptoms in patients with schizophrenia in Shiraz, Iran. *BMC psychiatry*. 2012; 12.(1):48.
6. Nadem Booeini M, et al. Attitude of schizophrenic patients' care givers about their method of patient caring at home. *Holistic Nursing And Midwifery Journal*.2013; 23(1): 54-62.
7. Koujalgi Sateesh R, Shobhadevi R. Family burden in patient with schizophrenia and depressive disorder: A comparative study. *Indian Journal of Psychological Medicine*. 2013;35(3): 251.
8. Panayiotopoulos C, Pavlakis A, Apostolou M. Family burden of schizophrenic patients and the welfare system; the case of Cyprus. *Int J Ment Health Syst*. 2013; 7(1):13.
9. Chakrabarti S. Family interventions in schizophrenia: Issues of relevance for Asian countries. *World journal of psychiatry*. 2011; 1(1):4.
10. Loga, Slobodan, et al. Chronic illness and family: impact of schizophrenia and crohn's disease on the family quality of life. *Psychiatria Danubina*. 2012; 24(4): 359-366.
11. Chien Wai T, Wong KF. A family psychoeducation group program for Chinese people with schizophrenia in Hong Kong. *Psychiatric Services*. 2007; 58(7): 1003-1006.
12. Galderisi S, et al. The influence of illness-related variables, personal resources and context-related factors on real-life functioning of people with schizophrenia. *World Psychiatry*. 2014;13(3): 275-287.
13. Song Y, et al. Using focus groups to design a psychoeducation program for patients with schizophrenia and their family members. *International journal of clinical and experimental medicine*. 2014; 7(1): 177.
14. Dixon L, Adams C, Lucksted A. Update on family psychoeducation for schizophrenia. *Schizophrenia Bulletin*. 2000; 26(1): 5.
15. Xia J, Merinder L, Belgamwar M. Psychoeducation for schizophrenia. *Cochrane Database Syst Rev*.2011;6.
16. Eack M, et al. Quality of life for persons living with schizophrenia: more than just symptoms." *Psychiatric rehabilitation journal*. 2007; 30(3): 219.
17. Shimazu K, et al. Family psychoeducation for major depression: randomised controlled trial. *The British Journal of Psychiatry*. 2011; 198(5): 385-390.
18. Twamley W, et al. Supported employment for middle-aged and older people with schizophrenia. *American journal of psychiatric rehabilitation*. 2008; 11(1): 76-89.
19. Lotfi F, Pasha Sharifi H, Seifi M. Effectiveness of family psychoeducation (atkinson and coia model) in general health of families coping with schizophrenia. *Andisheh va Raftar (Applied Psychology)*. 2010; 5(17):65-78.
20. Haller Chiara S, et al. Recent advances in understanding schizophrenia. *F1000prime reports*.2014;6.
21. Barry Sarah JE, Gaughan T, Hunter R. *Schizophrenia Search date May 2010*.2012.
22. Yoshii H, et al. Effect of an education program on improving knowledge of schizophrenia among parents of junior and senior high school students in Japan. *BMC public health*. 2011;11(1): 323.