

Exploring interventions for caregivers of individuals with mental illness and analyzing their interactions. A brief literature review

Savvidou Despoina¹

Summary

Effects on the health of caregivers of the mentally ill are common. By allowing relatives to express the unpleasant feelings they experience, after the onset of the disease, the correct distinction between them and the patient can be achieved and their mental resilience can be strengthened.

This work will mention the emotional difficulties of the caregivers, their needs, and their participation in the process of acceptance of the disease, with the aim of smooth cooperation with the patient, will be mentioned.

Caregivers have to deal with communication problems with the mentally ill, social isolation, and financial burdens. The literature review shows that the majority of caregivers are women and often experience a feeling of permanent fatigue, depression, and pain.

It is important to understand the difference between love and boundary. Already for most relatives, involuntary hospitalization is in itself a traumatic event. Caregivers need early professional help to avoid the irreversible effects of the disease.

Finally, recommendations are given to the relatives for a better coexistence with the patient.

Keywords: caregivers, mentally ill, boundary setting, family, communication, expressed emotion

Introduction

Research shows that the percentage of people with severe mental illness who live with their relatives ranges between 40% in the United States, over 60% in Africa, and over 90% in China (Rafiyah et al, 2011) (El-Tantawy AMA et al, 2010), (M Berg-Weger, 2000)

The responsibility of care falls mainly on women, daughters, and wives, either because they deeply believe that this role is theirs or because of the social environment. (Donelan, et al 2001)

Researchers (Teixeira, L.A. et al 2022) argued that caregivers with a higher level of education are associated with a more significant burden, attributing it to the increased demands and expectations they may have on themselves and others.

Considering the WHO definition of health, where apart from the absence of disease, the person's full physical, mental, and social well-being is required, we understand that the caregiver of the mentally ill needs a holistic approach from the health system. (WHO, 1946) The same is presented in the psychosocial model of Engel (1980) where illness and health result from an interaction between biological, psychological, and social factors.

Expressed emotion is often cited in the literature as one of the most studied psychosocial constructs in the field of psychiatry (McCleary & Sanford, 2002) and is a measure reflecting the range of criticism and emotional hyperarousal expressed by a primary relative towards a member with a disability (Hooley, 2007).

It may be that psychoeducation interventions in the family improve the attitude of its members toward mental illness, but not their health problems. (José Gutiérrez-Maldonado et al (2008)

What are the health implications for caregivers? How are their interpersonal relationships affected? Is the family's standard of living affected? In this paper, a brief review of the international literature will be made.

The health effects of caregivers of the mentally ill

Despite the few studies that recognize positive outcomes for caregivers where they feel good and satisfied with themselves (Aadil Jan et al., 2010; Schulz R et al, 2008; Vasoontara Y, 2012) caregiving has all the characteristics of an experience of chronic stress to be used as a model for studying the health effects of chronic stress (Saunders J. 1999).

¹ School of Medicine, Aristotle University of Thessaloniki, Greece

Vaitsa Giannouli, School of Medicine,

Aristotle University of Thessaloniki

54124 Thessaloniki, Greece

E-mail: giannouliv@hotmail.com

A study conducted in Greece found that caregivers, especially women and younger people, endure significant stress, anxiety, and depression, affecting their quality of life. (Oikonomou et al., 2024)

Most of the families have limited sources of social and emotional support, little information about the disease, and no education on how to cope with the patient's symptoms (Dixon et al. 1999). Often, family members of the mentally ill feel isolated from sources of social and emotional support and feel neglected by mental health professionals (Magliano et al. 2002; Economou et al. 2013). It is known from decades of research that caring for a person with psychosis is often a burden on families (Winefield and Harvey 1993). More specifically, two-thirds of caregivers feel significantly burdened. Relatives face emotional and financial problems and often suffer from various health problems. Potentially negative effects of caring for a patient with mental illness on the caregiver's psychological well-being may be ongoing anxiety, a sense of loss, the tension between caregiver and relative, and psychological stress. (Stephens J. et al. 2011)

Schizophrenia caregivers report lower quality of life than caregivers of people with other illnesses (Gkintoni et al., 2017).

The burden of a family with a mentally ill person affects the financial situation, daily activities, leisure time, health, and behavior of the family, and provokes emotions such as anxiety, guilt, depression, critical comments, and aggressive behavior (Oikonomou M. 2010)

Research conducted in the UK reported that carers' psychological distress (anxiety, depression, and insomnia) was twice that of the general population. (Aldridge M & Hughes I., 1992). Caregivers of people with schizophrenia are more likely to experience sleep difficulties, insomnia, pain, and anxiety (Nooraen, S. et al., 2023)

Hernandez & Barrio (2015) investigated the interpersonal relationships between Latino family members with an ill member. Research participants considered the impact on their interpersonal relationships to be the most challenging aspect of the illness. Most of these difficulties arose because of the behavior associated with the illness. Families noted how arguments and verbal and physical fights created a negative environment that affected the quality of family relationships. Similarly, several participants expressed that the isolation of the person with schizophrenia from others, possibly due to negative symptoms associated with the illness, made it difficult for family members to engage with the sufferer, thus affecting family relationships. Patients with psychosis are more socially isolated when more people live around them. (Domenico Giacco et al, 2022)

What are the effects of involuntary hospitalization on caregivers?

In Norway, research was carried out on the impact of involuntary hospitalization of patients on their carers.

Carers experience the process of involuntary hospitalization as a very negative experience. They report being treated as subordinate caregivers and not as sympathizers. The behavior of health professionals is perceived as offensive and increases their feelings of guilt. (Førde et al, 2016) Also mentioned is the great pressure exerted on caregivers regarding their relatives' involuntary medication during hospitalization. They often put pressure on the patients themselves, feeling guilty about the legal aspect of the matter. (Jaeger et al, 2019)

It is also necessary to focus on US research which describes the "period of high alert living", during which mothers anxiously await adult children to meet the criteria for involuntary hospitalization. This is a chaotic and scary time. Fear and uncertainty eventually overwhelm mothers' abilities to manage their children's behavior. They turn to the police or psychiatric assessment teams, restraining their children, but without psychiatric care. Mothers accept the consequences of being responsible for their children's involuntary hospitalization or staying home with their children if authorities do not proceed with involuntary hospitalization. While mothers recognized the necessity of involuntary hospitalization, they were not always able to access treatment due to the refusal of their adult children or because they did not meet the legal criteria for involuntary hospitalization (Copeland & Heilemann, 2008).

The needs of caregivers

The recognition of the role that the family plays in the manifestation and course of a member's psychotic experiences has been instrumental in the development of family therapeutic approaches to psychosis (Gracio et al., 2016.). There are several different family approaches in practice today. Some forms of family therapy start from the idea that the way of communication within the family and the emotional relationship between its members affect the mental state of the members (Zisi, 2002). It has also been found that specific patterns of emotional relationship and interaction between parents and children are related to the exacerbation of psychotic experiences in the child of the family who has received a diagnosis of psychosis (Zisi, 2013). Family therapy attempts to help family members understand what is happening to the member experiencing extreme situations, change their attitudes toward that member, and adopt more balanced and functional communication and relationship patterns.

A form of family intervention, called "psychoeducation" (McFarlane, 2000; Oikonomou et al., 2014; Pallis et al., 2015), focuses more on educating family members about psychosis so that they are better prepared to recognize and deal with any flare-ups of their relative's psychotic experiences. Other forms, of a more supportive type, try to help families cope with the difficulties they encounter in daily living and support their members with psychosis. Finally, a recent version of the family approach, called "open dialogue," involves both the person with psychosis and their family and others close to them in meetings, where they exchange views about what is happening to the person

experiencing intense mental pain, to reach a better understanding of what is happening and how both the person with psychosis and their loved ones can best manage it (Aaltonen et al., 2012. Seikoula & Alakare, 2012).

To relieve caregivers, it is also common to have self-help groups of siblings, parents, or more generally, relatives of people with psychosis (Fadden et al., 2012. Kefallinou, 2016).

Simple recommendations for caregivers

A) Caregiver and patient training in separating love from demarcation: During contact with the caregivers, it is pointed out that to achieve a long-term good coexistence of patient and caregivers, proper demarcation and in some way distancing from the disease should be done. Caregivers must understand that not everything depends on them, that it is not their role to endure, that they must seek professional help and have the courage to follow instructions.

B) The caregiver is grieving. It is reasonable for him to be able to express his pain and his sadness because he is faced with a chronic illness and a disability. Many dreams he had for the future of his child or relative are thwarted. The goal is to accept the changes, but at the same time to be optimistic that they can go together harmoniously. (Susan H. McDaniel, et al, 2005)

C) He is encouraged to participate in Social Support Networks because greater support from families, friends, and communities is associated with better health.

Culture, customs and traditions, and family and community beliefs influence health. How we deal with life's stresses and challenges all affect health. (<https://www.who.int/news-room/questions-and-answers/item/determinants-of-health>)

D) "There is a wisdom in emotions that we must accept," says Slovic. The challenge, therefore, is not so much the elimination of emotion, as the utilization of its power without distorting the scientific evidence. (Slovic P., 1999)?

E) On a case-by-case basis, the professional and the caregivers should see together what the patient can and cannot do. The feelings that caregivers have to process are the sympathy for their relative on the one hand and the suspicion that they are being deliberately taken advantage of on the other. (Anderson et al 1986)

F) They should see what they have not managed well in the past, whether it is mismanagement of finances or overestimation of their strengths.

G) If the caregiver feels that he is being systematically taken advantage of, he languishes and has depressive symptoms and a feeling of permanent fatigue. Rationalizing and recognizing his feelings can prevent them.

H) The caregiver is encouraged to engage in social activities outside the family (Magliano et al, 2005)

F) The family must identify what can be changed and accept what cannot be controlled. (Susan H. McDaniel, et al, 2005)

CONCLUSIONS

The necessity of close cooperation between caregivers and mental health professionals in families with a member suffering from a chronic mental illness is frequently observed. Unfortunately, not enough research has been carried out at a global level, recording those variables that determine the reduction of caregivers' stress. In that way, their quality of life can be improved. Certainly, through counseling psychotherapy, there will be relief, but the necessity, to define the factors that will help the daily coexistence and communication of the members continues to exist. The empowerment of the family and its members should be the main concern of health professionals. (Georgaka & Zisi, 2022)

References

- Γεωργάκα Ε. & Ζήση Α. Ζώντας με την ψύχωση, Κάλλιπος, 2022
- Ζήση, Α. (2002). Επανάταξη χρόνιων ψυχικά πασχόντων: Εμπειρικά ευρήματα, Νέες προσεγγίσεις και προοπτικές. *Τυπωθήτω*
- Ζήση, Α (2013). Κοινωνία, κοινότητα και ψυχική υγεία. *Τυπωθήτω*.
- Κεφαλληνού, Μ. (2016). Αμοιβαία υποστήριξη συγγενών και φίλων στο χώρο της ψυχικής υγείας: Πώς νοηματοδοτούν τα μέλη μιας ομάδας την εμπειρία τους. *Τετράδια Ψυχιατρικής*, 4, 149-159.
- Οικονόμου Μ., (2010), Ο ρόλος της οικογένειας στην ψυχοκοινωνική αποκατάσταση, Σε: Χριστοδούλου Γ.Ν., Κονταξάκης Β.Π., & Οικονόμου Μ., Προληπτική Ψυχιατρική. Αθήνα: ΒΗΤΑ Ιατρικές Εκδόσεις, 181-186.
- Οικονόμου, Μ., Πάλλη, Α., Πέππου, Λ. Ε., Λουκή, Ε., Πατελάκης, Α., Κολοστούμπης, Δ., & Παπαδημητρίου, Γ. (2014). Ψυχοεκπαίδευση & Συμπεριφορική Θεραπεία Οικογένειας στη σχιζοφρένεια: Κλινική εφαρμογή στην Ελλάδα. *Γνωσιακή - Συμπεριφοριστική Έρευνα & Θεραπεία*, 1(1), 15-24.
- Πάλλη, Α., Καλαντζή-Αζίζι, Α., Πλουμπίδης, Δ., Κοντοάγγελος, Κ., & Οικονόμου, Μ. (2015). Ομαδική ψυχοεκπαιδευτική παρέμβαση σε συγγενείς ασθενών με σχιζοφρένεια. *Ψυχιατρική*, 26, 243-254.
- Σεϊκούλα, Τ., & Αλακάρε, Μ. (2012). Ανοιχτοί διάλογοι. Στο Π. Λέμαν, Π. Στάστι & Α. Εμμανουηλίδου (Επιμ. Έκδ.), *Αντί της ψυχιατρικής: Εναλλακτικά μοντέλα συνάντησης με τον ψυχικό πόνο* (σελ. 195-216). Νησίδες.
- Aadil Jan S, Ovais W, Javed L. Psychological Distress in Carers of People with Mental Disorders. *BJMP*. 2010;3(3):327.
- Aaltonen, J., Seikkula, J., & Lehtinen, K. (2012). The comprehensive Open-Dialogue approach in Western Lapland: I. The incidence of non-affective psychosis and prodromal states. *Psychosis*, 3(3), 179-191. <https://doi.org/10.1080/17522439.2011.601750>
- Anderson Carol, Douglas J. Reiss , Gerard E. Hogarty Schizophrenia and the Family: A Practitioner's Guide to Psychoeducation and Management Hardcover – May 12, 1986
- Berg-Weger M. "Depression as Mediator: Viewing Caregiver Well-Being and Strain in a Different Light," *Families in Society* March/April 2000
- Copeland, Darcy Ann; Heilemann, MarySue V Getting "to the Point": The Experience of Mothers Getting Assistance for Their Adult Children Who Are Violent and Mentally Ill
- Nursing research (New York), 05/2008, Τόμος 57, Τεύχος 3
- Dixon L. Scott J., Lehman A., Postrado L., Goldman H. and McGlynn E. (1999). Services to families of adults with schizophrenia: From treatment recommendations to dissemination. *Psychiatric Services*, 50, 233-238
- Donelan, K.; Falik, M.; DesRoches, C.M. Caregiving: Challenges and Implications for Women's Health. *Women's Health Issues* 2001, 11, 185–200. [CrossRef]
- Economou M., Palli A. and Peppou L.E. (2013). Individual family psychoeducation for schizophrenia: Findings from a large training program for mental health staff. Unpublished paper.
- Engel GL. The clinical application of the biopsychosocial model. *Am J Psychiatry*. 1980 May;137(5):535-44.
- El-Tantawy AMA, Raya YM, Zaki A-SMK. Depressive Disorders among Caregivers of Schizophrenic Patients in Relation To Burden of Care and Perceived Stigma. *Current Psychiatry*. 2010;17(3):15–25.
- Fadden, G., James, C., & Pinfold, V. (2012). Caring for yourself – Self help for families and friends supporting people with mental health problems. *White Halo Design*.
- Førde, Reidun; Norvoll, Reidun; Hem, Marit Helene ; More... Next of kin's experiences of involvement during involuntary hospitalisation and coercion *BMC medical ethics*, 11/2016, Volume 17, Issue 1
- Gkintoni, E.; Pallis, E.G.; Bitsios, P.; Giakoumaki, S.G. Neurocognitive performance, psychopathology and social functioning in individuals at high-genetic risk for schizophrenia and psychotic bipolar disorder. *Int. J. Affect. Disord*. 2017, 208, 512–520.
- Giacco Domenico at all,2022,Neighbourhood characteristics and social isolation of people with psychosis: a multi-site cross-sectional study *Soc Psychiatr Epidemiol*, 2022 Sep;57(9):1907-1915.doi: 10.1007/s00127-021-02190-x. Epub 2021 Nov 17.
- Gracio, J., Goncalves-Pereira, M., & Leff, J. (2016). What do we know about family interventions for psychosis at the process level? A systematic review. *Family Process*, 55(1), 79-90. <https://doi.org/10.1111/famp.12155>
- Gutiérrez-Maldonado José 1, Alejandra Caqueo-Úrizar, Marta Ferrer-García,(2008) Effects of a psychoeducational intervention program on the attitudes and health perceptions of relatives of patients with schizophrenia Randomized Controlled Trial *Soc Psychiatry Psychiatr Epidemiol*. 2009 May;44(5):343-8. doi: 10.1007/s00127-008-0451-9. Epub 2008 Nov 3.
- Hernandez, Mercedes; Barrio, Concepción Perceptions of Subjective Burden Among Latino Families Caring for a Loved One with Schizophrenia *Community mental health journal*, 11/2015, Τόμος 51, Τεύχος 8
- Hooley, Jill M Expressed emotion and relapse of psychopathology *Annual review of clinical psychology*, 01/2007, Τόμος 3,
- Jaeger, Susanne; Hüther, Franziska; Steinert, Tilman Refusing medication therapy in involuntary inpatient treatment—A multiperspective qualitative study *Frontiers in psychiatry*, 05/2019, Τόμος 10, Τεύχος MAY
- Magliano et al. (2002), The impact of professional and social network support on the burden of families of patients with schizophrenia in Italy. *Acta Psychiatrica Scandinavia*, 106, 291- 298.
- McCleary, Lynn; Sanford, Mark Parental expressed emotion in depressed adolescents: prediction of clinical course and relationship to comorbid disorders and social functioning *Journal of child psychology and psychiatry*, 07/2002, Τόμος 43, Τεύχος 5
- McDaniel Susan, Jeri Hepworth , Thomas L. Campbell , Alan Lorenz *Family-Oriented Primary Care*, 2005, Springer
- McFarlane, W. R. (2000). Psychoeducational multi-family groups: Adaptations and outcomes. In B. V. Martindale, A. Bateman, M. Crowe & F. Margison (Eds.), *Psychosis: Psychological approaches and their effectiveness* (pp. 68-95). Gaskell.
- Nooraeen, S.; Bazargan-Hejazi, S.; Naserbakht, M.; Vahidi, C.; Shojaerad, F.; Mousavi, S.S.; Malakouti, S.K. Impact of COVID-19 pandemic on relapse of individuals with severe mental illness and their caregiver's burden. *Front. Public Health* 2023, 11, 1086905.[PubMed]
- Oikonomou, Vasiliki; Gkintoni, Evgenia; Halkiopoulos, Constantinos ; More.. Quality of Life and Incidence of Clinical Signs and Symptoms among Caregivers of Persons with Mental Disorders: A Cross-Sectional Study] *Healthcare (Basel)*, 01/2024, Τόμος 12, Τεύχος 2
- Oldridge M, Hughes I. Psychological well-being in families with a member suffering from schizophrenia. *Br J Psychiatry*. 1992;161:249–51
- Rafiyah Imas, S.Kp, Assoc. Prof. Dr. Wandee Sutharangsee. Burden on Family Caregivers Caring for Patients with Schizophrenia and Its Related Factors : *Review Nurse Media J Nurs*. January 2011; 1(1):29–41.
- Saunders J. Family functioning in families providing care for family members with schizophrenia. *Issues Ment Health Nurs*. 1999;20(2):95–113
- Slovic P. Trust, emotion, sex, politics, and science: surveying the risk-assessment battlefield. *Risk Anal* 19(4):689–701 (1999); doi: 10.1111/j.1539-6924.1999.tb00439.x.
- Schulz R, Sherwood PR. Physical and Mental Health Effects of Family Care giving. *J Social Work Educ*. 2008;44(3):105–10.
- Stephens J.R., Farhall J., Farnan S. and Ratcliff M., (2011), An evaluation of Well Ways, a family education programme for carers of people with a mental illness, *The Royal Australian and New Zealand Journal of*

Psychiatry, 45, 45-53. people with chronic schizophrenia. Schizophrenia Bulletin, 19(3), 619-625.

Teixeira, L.A.; Borges, M.d.C.; de Abreu, D.P.H.; Ribeiro, K.B.; Shimano, S.G.N.; Martins, L.J.P. Caregivers of older adults in palliative care: Level of burden and depressive symptoms. *Fisioter. Mov.* 2022, 35.

Vasoontara Y, Sam-ang S, Sleigh AC. Psychological distress and mental health of Thai Caregivers. *Psychol Well being: Theory, Res Pract.* 2012;2(4):2-11

WHO. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June 1946, and entered into force on 7 April 1948. (n.d.).

Winefield H.R. and Harvey E.J. (1993), Determinants of psychological distress in relatives of people with chronic schizophrenia *Schizophr Bull* 1993;19(3):619-25.doi: 10.1093/schbul/19.3.619.(Pub Med)