



THE WORK OF FAMILIES AND THE BURDEN ARISING FROM CARING FOR PEOPLE SUFFERING FROM SEVERE MENTAL ILLNESS¹

*O trabalho das famílias e o ônus advindo do cuidado
com pessoas em sofrimento psíquico grave*

*El trabajo de las familias y la carga que supone el cuidado de
personas que padecen enfermedades mentales graves*



Paollo Borghi  

¹ Part of the initial structuring of this text relied on **artificial intelligence** tools for text organization, which were revised, adapted, and validated by the authors.

Abstract

In psychiatry, therapeutic models have excluded family members from care management, restricting the person in distress. The aim of this essay was to describe the work developed with family members who bear the burden of caring for people in severe mental distress, carried out at the Department of Mental Health in Trieste since 1987. This program emerged from initiatives providing opportunities for information, participation in services, greater knowledge among family members, and effective mutual support programs, with the family actively involved in organizing the therapeutic project and in educational and informational programs. When the family is left alone, it faces the weight of responsibility in isolation, dominated by despair, shame, and loss of hope. Finally, the involvement of families in the work process with people in severe distress is relevant for the family members, the person, and the service, as an expanded form of mental health care.

Keywords: Family; Severe mental distress; Expanded clinical practice

Resumo

Na psiquiatria os modelos terapêuticos excluíram os familiares no manejo do cuidado, restringindo a pessoa em sofrimento. O objetivo deste ensaio foi descrever o trabalho desenvolvido com familiares que cuidam com ônus de pessoas em sofrimento psíquico grave realizado no Departamento de Saúde Mental de Trieste, desde 1987. Este programa surgiu com iniciativas de oportunidades de informação, participação nos serviços, maior conhecimento entre os familiares e programas efetivos de ajuda mútua, com envolvimento da família de forma ativa na organização do projeto terapêutico e nos programas educativos e informativos. Quando a família é deixada sozinha, enfrenta o peso da responsabilidade no isolamento, dominada pelo desespero, vergonha e perda de esperança. Finalmente, o envolvimento das famílias no processo de trabalho de pessoas em sofrimento grave é relevante para os familiares, a pessoa e o serviço, como uma forma ampliada de cuidado em saúde mental.

Palavras Chaves: Família; Sofrimento psíquico grave; Clínica ampliada

Resumen

En psiquiatría, los modelos terapéuticos han excluido a los familiares de la gestión de la atención, limitando así a la persona que sufre. El objetivo de este ensayo fue describir el trabajo desarrollado con familiares que asumen la carga del cuidado de personas con sufrimiento mental grave, llevado a cabo en el Departamento de Salud Mental de Trieste desde 1987. Este programa surgió de iniciativas que brindan oportunidades de información, participación en los servicios, mayor conocimiento entre los familiares y programas efectivos de apoyo mutuo, con la familia involucrada activamente en la organización del proyecto terapéutico y en programas educativos e informativos. Cuando la familia se queda sola, enfrenta el peso de la responsabilidad en aislamiento, dominada por la desesperación, la vergüenza y la pérdida de esperanza. Finalmente, la participación de las familias en el proceso de trabajo con personas con sufrimiento mental grave es relevante para los familiares, la persona y el servicio, como una forma ampliada de atención a la salud mental.

Palabras clave: Familia; Sufrimiento mental grave; Práctica clínica ampliada

Introduction

This essay¹ aims to describe the work developed with families regarding the burden of caring for and accompanying people experiencing severe psychological distress, carried out at the Mental Health Department (DSM) of Trieste. It reflects on the relevance of supporting and caring for family members who live within this context.

This reflection was presented in May 2025 at the 3rd International Congress on Mental Health: *Franca and Franco Basaglia School – The Right to Mental Health and Care in Freedom*, contributing to the discussion on the importance of the work carried out at the Mental Health Department (DSM) of Trieste, focused on support and assistance for family members who care for service users.

Throughout the history of psychiatry, therapeutic models alternated over time, and for a long period they excluded family members, believing that care should focus solely on the person experiencing suffering, distancing families from participation in the care process.

In Italy, as in many other parts of the world, during the existence of psychiatric asylums, mental illness was explained exclusively from an organic perspective. In fact, within the medical-biological model, mental illness was viewed and interpreted in anatomical-physiological terms and considered hereditary. Clinical records therefore contained little information about family members and family dynamics, including only whether or not there were “hereditary burdens” related to the individual’s disorder. In this context, the family member became regarded as the main cause of the pathology affecting their loved one, generating feelings of guilt and shame among families.

The psychoanalytic model recognizes that individual development takes place through relationships maintained with family figures, moving away from an exclusively organic interpretation and incorporating other dimensions into the relationship with the person. In this model, family relationships are important because they positively or negatively influence the family member’s way of living and allow the development of their ability to relate to others. However, in the practice of mental health services, although the family was valued, it still remained in the background and was not actively involved in therapy, which remained centered mainly on the individual experiencing psychological suffering.

Another approach that considers the family is the systemic-relational model, which describes the family as a system understood as a group that tends to maintain its own balance, in which members mutually influence one another. In this model, the family is analyzed through the reactions among its members, verbal and non-verbal communication, alliances, and so forth. Thus, the family itself becomes the “object” to be analyzed and modified.

¹ Parte da estruturação inicial deste texto foi auxiliada por uma ferramenta de inteligência artificial (ChatGPT, da OpenAI), sendo posteriormente revisada, adaptada e validada pelo autor.

The radicalization of some interpretations regarding conditioning within the family nucleus led, especially in Anglo-Saxon countries during the 1960s and 1970s, to the anti-psychiatry movement, which emphasized irrational dynamics structured within the family, comparing it to other total institutions such as prisons and asylums.

Laing (1983) stated that everyone who studied the families of people diagnosed with schizophrenia agreed that the apparent irrationality of the individual finds, largely or entirely, its rationality within the family context of origin. At this point, the family itself appears irrational. Positively, this contributed to reducing the stigma surrounding mental illness and questioning the incomprehensibility of the “mad person,” valuing the meaning of various behaviors such as rebellion, isolation, refusal, and others.

In many Western countries, the beginning of deinstitutionalization favored increased contact and coexistence between former asylum residents and their families. From these reconnections emerged another approach: psychoeducational intervention, which provides families with simple tools to improve coexistence with the person, accept them, and face periods of crisis with less tension and anguish. Family interventions are considered an essential component in the treatment of severe psychoses (American Psychiatric Association, 2023).

Psychoeducational guidance programs are positively evaluated both by family members—who acquire more tools to face crises, greater knowledge about psychological suffering, and increased attention to the needs of their loved one—and by the mental health professionals involved. In this context, the concept of “expressed emotion” was also introduced, since it was observed that in some families it was very intense and in others less so. Although a direct family cause for the onset of illness was excluded, it was considered that family dynamics could influence its course.

Scales measuring hostility, criticism, emotional involvement, warmth, and positive comments began to be included, for example within the vulnerability-stress model, in which expressed emotion appears as a stress factor strongly associated with relapses (Hooley et al., 1995).

The Beginning

Within this historical trajectory, Italian psychiatric care legislation (Law 833/1978), by declaring the end of the asylum institution, promoted the organization of territorial mental health services and guaranteed the right to care and citizenship for individuals institutionalized in psychiatric hospitals. Thus, service users, their families, and citizens became directly involved in therapeutic work.

In this sense, since 1987 the Mental Health Department of Trieste has promoted a program of initiatives aimed at creating opportunities for information, participation in services, greater understanding among family members, and the construction of effective mutual-help programs.

The program for families emerged from practical experience, which demonstrated that when families are involved throughout the care process of a person experiencing psychological

suffering, they become active participants in organizing the therapeutic project and also take part in educational and informational programs. Conversely, when families are left alone, they face the burden of responsibility in isolation, dominated by despair, shame, and loss of hope.

About the Family Program

Intervention aimed at families also arose from the need to address, in moments specifically dedicated to them, the difficulties experienced in daily life, encouraging stress reduction and greater exchange among participants.

Over time, it was observed that participation in these programs improves quality of life, family functioning, and social functioning, while also reducing relapses and crises. Research highlights two relevant aspects: (i) psychoeducational intervention significantly reduces relapses (Falloon, 1986); and (ii) there are two problematic contexts that directly affect family caregiving (Hoenig and Hamilton, 1966).

These two problematic contexts are: (i) objective issues, such as practical problems involving financial and work-related difficulties, time devoted to caregiving, reduction of leisure time and social relationships, and, especially for women, abandoning employment or career opportunities; and (ii) subjective issues, such as psychological problems experienced by family members, suffering due to the loss of the idealized image of the child, anxiety, depression, psychosomatic symptoms, feelings of guilt and shame, disorientation caused by lack of information, and social isolation.

To reduce these problematic contexts, concrete support from services is necessary, including therapeutic group work, appreciation of family members, and exchange of experiences. Furthermore, it is important that family members acquire broader knowledge about the pathology in order to help reduce feelings such as guilt, challenge prejudices, value their own history, and recognize the capacities of their relative.

The family program makes it possible to transform relationships among family members as well as within services, improving the capacity to face problems and crises, reducing demands on services, and decreasing relapses. In addition, it stimulates new forms of intervention and the active participation of everyone involved.

The work with families was structured around three approaches with their respective objectives, defending rights and combating discrimination and prejudice:

- a) **Psychoeducational:** improvement of knowledge about psychological suffering, expectations, and limits of treatment, carried out in ten biweekly meetings;
- b) **Psychotherapeutic:** encouraging exchange of experiences, stress reduction, support, and emotional assistance in group settings;
- c) **Solidarity network approach:** encouraging the expansion of social networks, self-help groups, combating isolation, and promoting mutual support.

The psychoeducational meetings address topics such as: (i) course presentation; (ii) mental disorder: explanatory models; (iii) pathologies; (iv) the family and severe disorders; (v) crisis: understanding and prevention; (vi) therapeutic projects and rights; (vii) psychopharmaceuticals; (viii) rehabilitation and social inclusion; (ix) recovery time and quality of life; and (x) coping techniques and support networks.

For Rotelli (1990), deinstitutionalization does not reside in cure itself, but in emancipation, in the creation of new models and opportunities, demystifying “madness.” By deconstructing a body of knowledge that had supported the foundations of Psychiatry since the Enlightenment, the notion of madness as alienation, error, or dangerousness can be replaced by the notion of difference, life production, and subjectivity. In this sense, the construction of new models that foster possibilities for social inclusion, appropriation of citizenship rights, and co-responsibility between the family and the service is highly relevant, thereby reducing the burden placed upon families.

Finally

Understanding the importance of involving families in the work process of people experiencing severe or chronic psychological suffering demonstrates how relevant this process is in benefiting the family, the individual, and the service itself, constituting a broader form of mental health care.

The program for families of people experiencing severe or chronic psychological suffering, carried out in Trieste, Italy, and presented in this article, contributes to understanding the complexity and importance of family members in caregiving, as well as the involvement of all actors, who should be encouraged through information, therapeutic support, and the expansion of support and care networks.

We conclude these reflections through the paradigm of deinstitutionalization, which shifted the organizational structure of the mental health system by decentralizing it and moving beyond a purely sanitary perspective, renewing an entire system of knowledge and mental health care, while recognizing service users and family members as agents of knowledge.

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