

The role of UNASAM – National Union of Associations for Mental Health in Italy

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Summary. This paper, after an introduction on the origin, development and principal aims of the National Union of Associations for Mental Health (UNASAM), briefly describes what happened in the last 30 years in the field of mental health in Italy. This period covers roughly the lifespan of the Italian Law 180, from the beginnings, the closure of psychiatric hospitals, to the difficulties of present days. The second part of the paper is a summary of a study commissioned to UNASAM by Istituto Superiore di Sanità and conducted in collaboration with the Istituto di Ricerche Farmacologiche “Mario Negri” of Milan. This research was aimed at evaluating the quality of mental health services in four Italian Regions. Members of patients’ families participated with enthusiasm, filling up a questionnaire and engaging in fieldwork, which required more than 3000 working hours and produced significant and useful results.

Key words: mental health, mental health associations, mental health services.

Riassunto (*Il ruolo dell’UNASAM – Unione Nazionale delle Associazioni per la Salute Mentale in Italia*). L’articolo inizia con un’introduzione sull’origine, sullo sviluppo e sugli obiettivi principali dell’UNASAM (Unione Nazionale delle Associazioni per la Salute Mentale). Segue una breve descrizione degli sviluppi in Italia nel settore della salute mentale negli ultimi 30 anni. Questo periodo coincide con la storia della Legge 180, dalla promulgazione, alla chiusura degli ospedali psichiatrici, fino alle attuali difficoltà. La seconda parte riguarda una ricerca commissionata all’UNASAM dall’Istituto Superiore di Sanità e condotta in collaborazione con l’Istituto “Mario Negri” di Milano, mirata alla valutazione della qualità dei servizi di salute mentale in quattro regioni italiane. I familiari dei pazienti hanno partecipato con entusiasmo a questo studio, compilando un articolato questionario e impegnandosi sul campo con oltre 3.000 ore di lavoro, il che ha consentito di raccogliere risultati assai interessanti e di notevole utilità.

Parole chiave: salute mentale, associazioni per la salute mentale, servizi di salute mentale.

INTRODUCTION

Since its foundation in 1993, the Italian National Union of Associations for Mental Health (UNASAM) is the major association of families operating in the field of mental health, being present in all the 20 Italian Regions. UNASAM is present in the board of two well-known international associations, namely the European Association of Families of Mentally Ill People (EUFAMI) and the World Association for Psychosocial Rehabilitation (WAPR).

The primary aim of UNASAM is to connect families and to represent them at three different levels: local, Regional and National Government. The main task is lobbying at these levels on several important issues, ranging from daily practices to development of laws, by-laws, and regulations. A secondary – but still significant – aim is to fight stigma and prejudice by educating people to a better knowledge and acceptance of mental health problems. A third aim is

to educate families by initiatives periodically organized by our association at different levels and in collaboration with reliable partners, such as the Trieste mental health services.

To describe what happened in Italy from 1978 till now, from the point of view of the “end users”, is not an easy job. We could identify two periods, the first one, from 1978 to 1983, and the second one from 1984 till now.

During the initial years of transition, the obstacles to the radical changes introduced by the new law, the numerous mistakes due to the scarcity of appropriate know-how and the chronic lack of money, drove the new psychiatric services to a condition close to collapse. In the same period, a few family associations began to appear in the country, mostly with a specific (negative) purpose: to repeal, or, at least, to amend the “horrible Law 180”. In the front of such an outcry, the voice of the Trieste model was too weak and difficult to be heard.

Nevertheless, the network of community mental health services began to grow and the civil rights of users became clearer and clearer to an increasing number of professional and lay people. New associations were started to support Basaglia's ideas and goals and to defend Law 180 from harsh criticism and often vicious attacks. Cooperatives were started, providing job opportunities to users, while in the whole country the new law led to an increasing attention to mental health issues. The Italian Regions enacted local laws for mental health within the national framework of Law 180 as incorporated in Law 833, promulgated a few months later, which founded the Italian National Health Service (Servizio Sanitario Nazionale, SSN) and therefore cancelled the previous affiliation of psychiatric hospitals to the administrations of the Provinces. The closure of psychiatric hospitals began to be mandatory and this process, in spite of considerable difficulties, was slowly completed. In the meantime, all local associations had become favourable to the new approach, giving birth to our new federation of associations, UNASAM.

The main problem to be faced during the second period (1984 till nowadays) has been the full implementation across the entire country of a complete network of community mental health services for sufferers and for their families. A parallel problem has been the need to counter the numerous attempts to repeal Law 180, in order to re-establish psychiatric hospitals and to increase the constraints on patients' right.

THE RESEARCH: "EVALUATION AND IMPROVEMENT IN MENTAL HEALTH CARE WITH ACTIVE PARTICIPATION OF VOLUNTARY ASSOCIATIONS"

In the years 2007-2008, the Istituto Superiore di Sanità commissioned to UNASAM a research project concerning the "Evaluation and improvement in mental health care with active participation of voluntary associations". This study was conducted in collaboration with the Istituto di Ricerche Farmacologiche "Mario Negri" of Milan. The main goals were:

- to set up and implement a model for participation of psychiatric patients' relatives to the evaluation of mental health services quality, with the aim of improving the know-how on evaluation methods and processes;
- to train patients' relatives in evaluation methods and procedures;
- to obtain from relatives meaningful indicators of service quality, in order to negotiate improvements in services based on evaluation findings.

METHODS

The research was a cross-sectional study of relatives' evaluation of service quality by means of an ad hoc questionnaire. To this purpose, various phases were planned:

1. following a review of the scientific literature, a

first draft of a questionnaire aimed at assessing the quality of Italian mental health services was developed;

2. this draft was evaluated and refined by two "focus" groups, whose members were affiliated to UNASAM;
3. the final version of the questionnaire was set up. It was a self-administered anonymous questionnaire, with yes/no answers consisting of 55 items grouped in 13 areas:
 - (i) quality of the physical environment
 - (ii) staff attitudes and behaviour
 - (iii) staff professional skills
 - (iv) accessibility
 - (v) response to emergencies
 - (vi) care program
 - (vii) effectiveness
 - (viii) information
 - (ix) home visits
 - (x) interagency collaboration
 - (xi) respect of privacy
 - (xii) individual rights, advocacy and legal protection
 - (xiii) modes of intervention (availability, perceived usefulness, and responses to requests);
4. two workshops were held with the family members in charge of questionnaire distribution in the services, in order to instruct the participants about basic principles of data collection, evaluation methods and data analysis; to provide indications about contacts with staff members and relatives; to give instructions for questionnaire distribution and filling;
5. identification of a sample of mental health services in four Italian Regions, followed by contact with the services and requests for permission to conduct research;
6. questionnaire distribution in the busiest days and hours to the relatives attending the services for any reason in a three month period between October 2007 and January 2009.

RESULTS

A total of 2259 questionnaires from 46 centres in four Regions were collected and analysed (*see Table 1*). The features of the respondents are shown in *Figure 1*.

Most respondents perceived service environment as good, with figures varying between 83% and 90%; however, a high proportion (47%) found it difficult to get in touch with the service by phone. The highest level of satisfaction for the environmental quality was recorded in Lombardy (93%) and the lowest in Latium (78%). Staff attitudes, behaviour and professional skills were satisfying for 76%-94% of the respondents, with differences among Regions (*e.g.*, 90% in Lombardy and 77% in Latium). Less than half of the respondents (43%) reported that they ever needed emergency interventions, and among those who needed them, 78% were satisfied with the help received. Most of the respondents (83%) said that they were

Table 1 | *The Italian Regions involved in the research*

Region	No. centres	Questionnaires		
		Distributed	Returned	Completed
Lombardy	20	1720	1328	1222
Sardinia	9	437	384	382
Emilia Romagna	13	429	368	368
Latium	4	381	288	287
Total	46	2967	2368	2259

informed on the project of care of their relative; 61% felt involved in its planning and 55% in the outcome assessment (Emilia Romagna 62%, Latium 42%).

As concerns the effectiveness of interventions, 80% said that they received adequate support from the service; 34% found meaningful mental health improvements in their relative; 38% found their relationship with their relative improved. Only 28% of the respondents thought that home visits were necessary, and 72% of those who needed such visits received them. There were significant differences between Regions, with 24% of respondents in Latium reporting a meaningful improvement of their relative's mental health versus 41% in Emilia Romagna.

Information on the health conditions of the relative were satisfying for 73% of the respondents, whereas information about family associations was satisfying for only 33%, and that about other sources of supports and care agencies for 25%. Only 37% answered that they were informed about the possibility of receiving financial help and/or legal aid. The collaboration between professionals within services was satisfying for 73% of the respondents, whereas the contacts between service professionals and general practitioners were adequate for only about one half (53%) of the family members.

The interventions received more frequently by the sick relatives were: psychiatric examination, 79%; in-

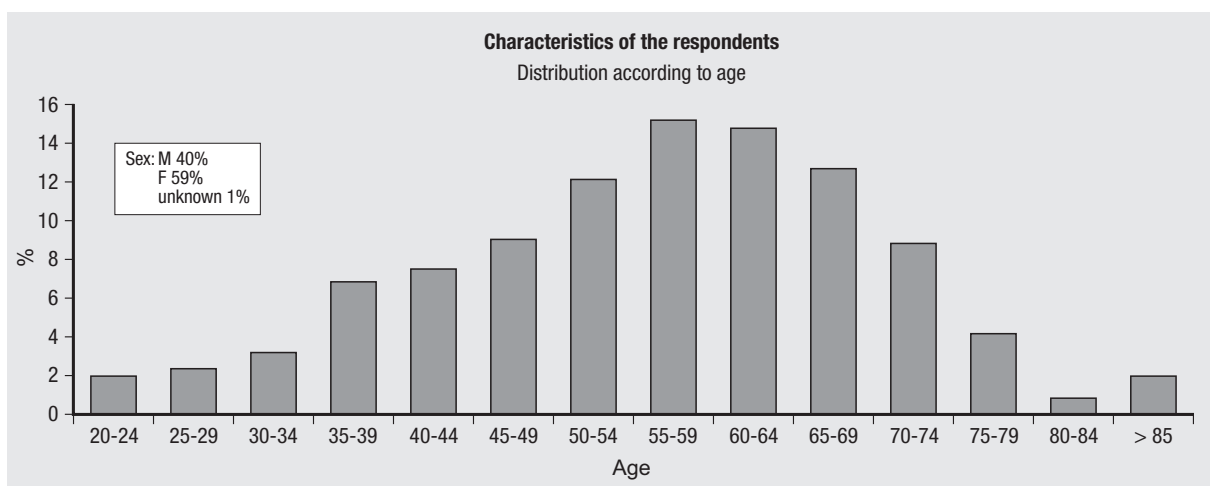
dividual psychotherapy, 35%; admission to psychiatric ward, 26%; financial help, 29%. More than one half of the respondents (61%) had one or more encounters with the psychiatrist, and 23% also received some psychotherapeutic intervention.

CONCLUSIONS

Family members participated with enthusiasm in both the research planning and its conduction, spending about 3000 hours of their time. The questionnaire used resulted to be an effective tool, which was easy to understand and to administer, even without the help of trained assistants; therefore, it would be useful to extend this research to all mental health services in all Italian Regions. The last section of the questionnaire, however, regarding the evaluation of interventions, should be improved, since family members had some problems in fully understanding how to use it.

As concern the results, we must take into account the common bias towards satisfaction and compliance usually found in satisfaction surveys. Dissatisfaction was at high levels concerning specific aspects of psychiatric care; therefore the following changes in the operation of mental health services appear to be necessary:

- clearer and fuller information should be provided about therapy programs;
- patients' families should be more extensively in-

**Fig. 1** | *Features of the questionnaire respondents.*

volved in programs aimed at monitoring and evaluating service quality;

- the relations between mental health personnel and general practitioners require considerable improvement;
- the readiness to perform home visits should be substantially increased;
- waiting lists must be shortened.

In conclusion, the relatives' evaluation pointed out significant differences in quality rating depending on which aspect of mental health care was considered. Overall, however, the results of the present assessment of service quality were more favourable than originally expected. A further step should be to find resources in order to extend evaluation programs to

users and to implement similar projects in all Italian Regions.

Acknowledgement

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