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The Recovery Orientation of a Farm Community for Severe Autism — Data from the DREEM-IT (Developing Recovery Enhancing Environment Measures — Italian Version)

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1. Introduction

Recent years have witnessed an increasing interest in the concept of ‘recovery’ in the field of mental health and psychiatry. Anthony (1993) described personal recovery as occurring in the presence of ongoing symptoms but involving ‘a way of living a satisfying, hopeful and contributing life even with limitations caused by illness’ (Anthony, 1993). Recovery from mental illnesses has been conceptualized to involve not only remission of symptoms and achievement of psychosocial milestones but also subjective changes in how persons appraise their lives and the extent to which they experience themselves as meaningful agents in the world (Jacobson & Greenley, 2001). Diverse forms of recovery are possible. In people with optimal outcome, recovery may produce important remission and changes, including the exit from mental health services for a long time period or, sometimes, permanently (Emsley et al, 2011). For other patients, it may mean continuing to receive medical, personal or social support, enabling people to get on with their lives (Emsley et al, 2011). However, in all conditions, the role played by the service in promoting, maintaining and restoring an adequate level of recovery for each patients is pivotal.

Autism is a neurodevelopmental disorder characterized by qualitative impairments in social interaction and communication skill, along with a restricted, repetitive, and stereotyped pattern of behavior and interests (APA, 2000). The diagnosis is lifelong and can be a major impediment to independent living. Therefore, autistic subjects need a long-term educational, psychiatric, and – in selected cases – medical support. It has been previously demonstrated that organized and structured forms of intervention, starting from early childhood and developing during all the different life stages, may improve outcome and quality of life in patients with autism (Howlin et al, 2009). It is therefore conceivable that diverse forms of recovery (e.g. optimal level of motivation, skills, social involvement) may be possible in autism.

There are no fully developed tools with which to evaluate the recovery orientation of a service, but the National Institute for Mental Health in England (NIMHE) has identified the Developing Recovery Enhancing Environments Measure (DREEM) (Ridgway & Press, 2004) as the most promising of an emerging group of recovery sensitive measures. The DREEM permits to collect data on the subjective recovery experience, highlighting the elements that people feel are important to their recovery. Additionally, this questionnaire rates the performance of the mental health service on diverse activities associated with each of these elements. Data from the DREEM may be used not only in evaluating the service but also in educating staff and patients about the recovery, in orienting services towards recovery, in assessing specific recovery oriented programs and supporting on-going quality improvement within the service (Allot et al, 2006).

This study explores the use of DREEM, as a tool to evaluate the effectiveness of recovery-based care in an Italian farm community center specifically designed for adult patients with autism and intellectual disability.

2. Material and methods

2.1. Linguistic validation

The DREEM is a 5-point Likert-type scale that ranges from 1 (Strongly Agree) to 5 (Strongly Disagree). Importantly, lower scores represent higher or more positive ratings and higher scores represent lower or less positive rating. All the questions are stated positively, so no reverse scoring is required. The linguistic validation of the Italian adaptation of the DREEM research tool consisted of three different phases. In the first phase, a board-certified psychiatrist (MB), native speaker of Italian, translated the original instrument into Italian. In the second phase, the Italian version was back translated into English by a professional translator of English background (MT). We compared the original questionnaire and the back translation for coherence and then formulated the initial Italian version of the instrument for patient testing. The third phase, the patient testing panel, was attended by 15 patients recruited in a psychiatric rehabilitation centre in Pavia, Italy. The participants were native speakers of the Italian language. The three steps resulted in the elaboration of the Italian version of the DREEM for the subsequent routine assessment of psychiatric patients or their caregivers.

2.2. Setting

The study was conducted in Cascina Rossago (San Ponzo Semola, Pavia, Italy). Established in 2002, this center is the first Italian farm-community specifically designed for autistic adults (See also Box 1 for more information). The ultimate goal is to improve the growth of each autistic subject in every area of life, using the rural, extended family community as a model. Activities include gardening, animal care, woodworking, carpentry, housekeeping. Additionally, daily schedule presents cognitive activities, stimulating concentration, attention, behavioral control and creative and expressive laboratories, such as music, painting, ceramics. Several sports are performed outside the farm, such as trekking, basket and sailboating. Other form of integration are represented by shopping locally, eating in local restaurants, selling the products of the farm during local festivals. Staff training, supervisions, didactics, meetings are strictly planned within and outside the farm with the special aim to update knowledge and to help care providers in understanding the features of autism and the treatment issues unique to this population. Medical and psychiatric care is assured by the daily presence of a psychiatrist with expertise in the field; this figure supervises activities, programs and staff performance within the farm.

2.3. Participants

The mothers of adult nonverbal subjects with severe autism were invited to take part in the project. The information about the project was given to 24 families at regular parent-caregiver meetings by one of the authors (SU). All patients with autism were recruited from a single farm community center specifically designed for individuals with autism (Cascina Rossago, San Ponzo Semola, Pavia, Italy). The diagnosis in each patient was made on the basis of the Autism Diagnostic Interview-Revised (ADI-R), Italian version (Lord et al, 2003). ADI-R is based on three separate scores. ADI-R domain score A quantifies impairment in social interaction (score range: 0–32), domain score BNV quantifies impairment in nonverbal communication (score range: 0–26), and domain score C quantifies restricted, repetitive, and stereotyped patterns of behavior and interests (score range: 0–16). Higher scores on each indicate worse condition. The cut-off scores of domain score A, domain score BNV, and domain score C are 10, 8, and 3, respectively. A DSM-IV diagnosis of ASD was made for all subjects. All subjects enrolled in the study had a Childhood Autism Rating Scale score > 40. All patients were assessed with Raven's Progressive Matrices, a measure of nonverbal IQ (Raven, 2000). Because of the severity and nonverbality of our patients, the Wechsler Intelligence Scale could not be used. The mothers were required to fill two specific sections (3 and 4) of the DREEM tool in a home-based fashion at two different time points (January 2009 and January 2010). Informed consent was obtained from each mother before examination.

2.4. Statistics

Descriptive statistics, including means and standard deviations were computed for each item of the DREEM. A paired t-test was computed to test the hypothesis that DREEM scores for each item could differ between the two different time points. Statistical significance was set at $p < 0.05$ in all the analyses for which the statistical software SPSS 17.0 version was used.

3. Results

Of the 24 mothers, 17 attended both interviews. Total mean scores in the section Organizational Climate were 1,5 in 2009 and 1,47 in 2010. Total mean scores in the section Recovery Markers were 1,6 both in 2009 and after one year. Statistical analysis indicated no difference for each item between the two different time points.

As depicted in Figure 1 and 2, in both sections and both administrations scores of all items were lower than two.

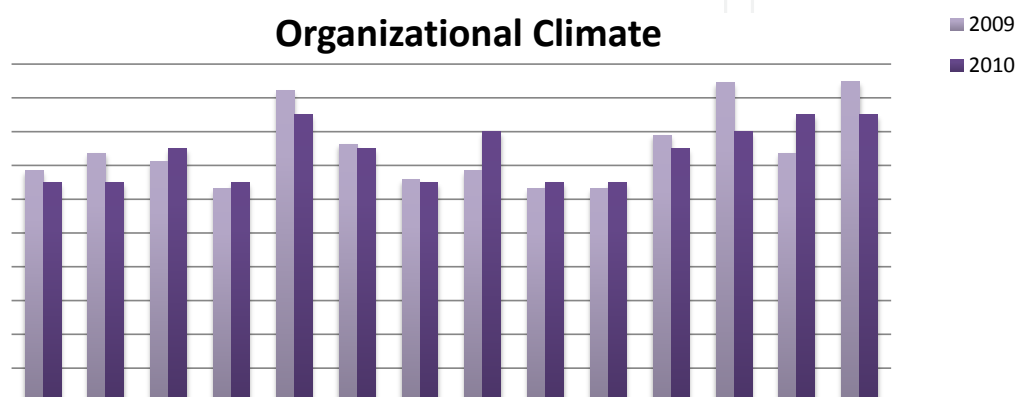


Figure 1. Column graph representing the Organizational Climate in Cascina Rossago

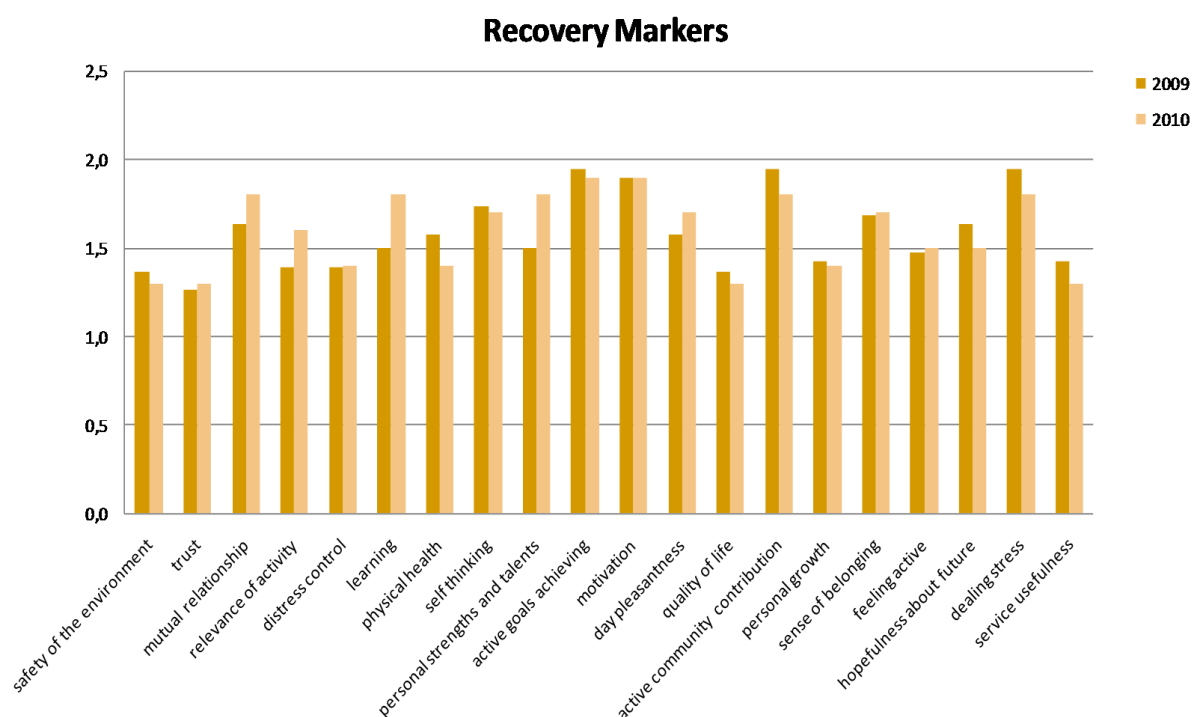


Figure 2. Column graph representing the Recovery Markers in Cascina Rossago

In the section Organizational Climate, the best results, i.e. a score lower or equal to 1.5, are showed in both administrations in the following items: “learning and growth”, “hopeful environment”, “encouraging service”, “friendly service”, “respect and esteem”, “safety and attractive service”, “welcoming staff” (Fig. 1). The item with a score equal or lower than 1.5 in the first administration but not in the second were “relationship” and “feedback relevance”, whereas the “creativity of the service” reaches the best score in the second administration (Fig. 1).

In the section Recovery Markers, the best results, i.e. a score lower or equal to 1.5, are showed in both administrations in the following items: “safety of the environment”, “trust”, “distress control”, “quality of life”, “personal growth”, “feeling active”, “service usefulness” (Fig. 2). The item with a score equal or lower than 1.5 in the first administration but not in the second were “mutual relationship”, “learning”, “personal strengths and talents”, whereas “physical health” and “hopefulness about the future” reach the best score in the second administration.

4. Discussion

Our study demonstrates that the section Organizational Climate and Recovery Markers of the DREEM may be useful to evaluate the recovery status in individuals with autism and severe intellectual disability. In fact, the 71% of the mother involved in this study attended both interviews, showing interest in this topic.

The two investigated sections show very good scores at both time points. Particularly, all items had always a score lower than two. Additionally, the absence of difference for each item between the two different time points suggests that a plateau has been reached in our study group.

This results highlight that the farm community is a rehabilitation model promoting the recovery process in autism. The results of both sections reveal that the investigated service is friendly, encouraging, safe and attractive. It favors learning and growth, respect and esteem and is targeted on improving the quality of life of the residents.

This rehabilitation approach, favoring communication, autonomy within a safe and structured framework, seems to be valid in contrasting the core dysfunctions of autism, favoring the growing of each autistic subject in every area of life.

As demonstrated in this work, if the framework is adequate, organized and targeted on patient needs, hopeful and stimulating life is possible also in the severe forms of social and cognitive impairment.

Box 1. General principles of intervention in Cascina Rossago

Constancy and stability are fundamental in planning and doing every activity carried out in Cascina Rossago. Beside these, a constant attention for the core elements of autism is always

required, accompanied by a firm organization and permanent education of the staff. Additionally, within the farm it is fundamental to do “real” work, aimed at specific and clear targets.

The rehabilitative approach of Cascina Rossago is based on four essential keywords:

- Ecological approach
- Subjectivity
- Shared problem solving
- Imitation

The ecological approach represents a constant connection between techniques, existential plan, care, organization of the life framework.

A rehabilitative approach targeted on subjectivity implements communication, expression and the ability of making choices, proposing activities fitted on individual motivation and aptitude.

The shared problem solving is probably the pivotal characteristic of Cascina Rossago. It is grounded on Meltzoff's theory “from shared actions to shared minds” (1993), applied to the specific case of subjects with severe social deficit. In an ecological and structured framework, where the relationship is assured by the constant presence of an expert care provider, the autistic subject may be more easily involved in social interaction. Patients and care-providers, together engaged in the activities, share actions, feelings, thoughts and emotions. In this rich context, autistic subjects, overcoming their social difficulties, may more spontaneously detect the “what” and “why” of human intentions.

The last keyword is imitation, necessary to the process of sharing actions and minds, as highlighted by Meltzoff (1993). In the last ten years, diverse theories have postulated an imitation deficit in autism associated with the presence of broken mirror neurons (Williams et al, 2001; Iacoboni & Dapretto, 2006). However, more recently, diverse Authors examined the broken mirror theory of autism concluding that the functioning of the mirror neuron system might be preserved in individuals with ASD to a certain degree (Southgate & Hamilton, 2008; Fan et al, 2010). They highlighted the necessity to study the mirror system within the larger context of the complex circuitries involving imitation, empathy and communication (Arbib, 2007; Southgate and Hamilton, 2009). People with autism show an enhanced automatic imitation effect (Bird et al, 2007). The fact that they can imitate but tend not to do so without instruction suggests that their difficulties arise from problems with knowing when and what to imitate, as a consequence of a reduced sensitivity to social cues. In fact, they can perform a variety of imitation tasks correctly when they are explicitly instructed to imitate (Hamilton et al, 2007).

A rehabilitation approach favoring interaction, communication, autonomy within a safe and structured framework, such as the farm community context, may contrast the core dysfunctions of autism with positive effects on the whole imitation system. As a consequence, imitation is possible within the farm and may be efficaciously used to favor interaction and communication.

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