

Group psychotherapy experiences for people with multiple sclerosis and psychological support for families

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In this article we describe our experience of group psychotherapy for patients afflicted with multiple sclerosis in the care of the Centre of Multiple Sclerosis of the Don Gnocchi Foundation in Milan, and an experience of psychological support to the patients' families. Multiple sclerosis, with its disability, chronic and unforeseeable features, brings about a series of changes in the patient's life. Considering the youthful age during which the disease arises, patients are obliged to review their own life plans in their family, social and working circles and have to face living with the chronicity and the loss of their own autonomy. Group psychotherapy was qualified as a preferred ambit to express and to share individual problems. The disease also involves the family: relatives must revise certain plans and projects made before. Psychological support could help relatives not only with the emotional load following on from the disease so that they do not feel alone in the patient's everyday care, but also with their own emotional management, in order to give them a listening space also for their distresses and fears. *Journal of NeuroVirology* (2000) 6, S168–S171.

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Introduction

Multiple sclerosis with its disability, chronic and unforeseeable features, brings about a series of changes in the patient's life that produce a progressive detachment from his expectation, hopes and life projects. This perception of detachment is above all about specific problems relating to the changes of his own bodily reference that shows itself in functional deficit, in the loss or in the reduction of important aspects of his own autonomy, in the fear of the disease progression, and in facing living together with the chronicity. The consequences of the psychosocial homeostasis on the person are considerable: in the family and working setting and in the social network. Within the family, relatives often are the more involved by the disease, which can cause a progressive detachment and change in the family setting (Cockerill and Warren, 1990). The necessity to replace the

patient in the duties and roles that he can no longer carry out, together with the important investment of relational, emotional, economic and time resources from relatives to look after the patient can change important aspects in the caregiver's life. The social and working sphere becomes the place where the patient has to work up again his own expectations and his own future projects (Burnfield and Burnfield, 1982). Sometimes the drastic reorganization of his own performances lead him inevitably to social withdrawal, self-depreciation, identity crises and loss of role and self-esteem (Foote *et al*, 1990). In the last few years in particular, literature has paid more attention to the life problematics of the multiple sclerosis patients (Murray, 1995). Considering the youthful age during which the disease arises, the patient is often a young person who is looking to realize his own life project. Instead, he has to face the very precarious situation the disease puts him in and he is forced to begin a difficult emotional adjustment that could always need redefining because of the unforeseeable characteristics of multiple sclerosis (Baretz and Stephenson,

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1981). Possible relapses always remind the patient of the continuous presence of the disease. Some researchers have underlined that the modality with which patients face the disease is related to certain variables like: the consequence of disability on the patient's social reality; and the basic personality structure of the patient and the support he can have from others. The latter is very important because it includes key factors like affection, closeness, help and sharing. The patient needs affectionate transactions like love, liking, respect and, at the same time, he needs confirmation transactions such as: assertion, to be recognised as a person and an active member in his family as well as in human society in general (Gulick, 1994). In a lot of studies it is possible to observe that the psychological support is very important for the individual's welfare not only for its direct contents but also for its ability to attenuate stressor effects; the quality of social relations is also considerable as regards the overall welfare of the patient and, on the other hand, the social dependence following the disease which causes an increase in the need of support (Crawford and McIvor, 1987; Cobb, 1976). It is also important to encourage and help the multiple sclerosis patient to maintain social and working activities. This allows the patient to still feel useful and able to contribute (Murray, 1995). Rehabilitating intervention consequently has to be aimed at relieving the distress and pain caused by living together with the chronicity and disability of the neurological disease (Landoni, 1989). The problems that relatives have to face are found to be an important therapeutic factor in the psychological support. Psychological intervention must then be aimed at finding resources: to help relatives bear up emotionally following on from the disease so that they do not feel alone in the patient's everyday care; and in managing their own emotions in order to give them a listening space for their distresses and fears. At first the Psychological Rehabilitation Course should include the individualisation of the essential phases about the patient's basic personality, the verification of the changes that the disease caused and the evaluation of the cognitive aspects and of possible psychiatric troubles within the new definition of the family network where the patient is included. Furthermore, it could be important to find, and moreover to encourage, the elaboration of motivational references of weighty life quality that, being over the goal of the adjustment to the pathologic condition, allow the patient to open some passages to his wishes and to the 'project of himself' (Knight *et al*, 1997). The rehabilitative project to change the multiple sclerosis patient should also involve the more external realities of the patient such as his family, his group, his working experience and his social life (Cockerill and Warren, 1990). We developed our experience inside the Centre of Clinical Psychology and Psychotherapy of the

Fondazione Don C. Gnocchi in Milan, and considered in particular group psychotherapy for multiple sclerosis patients and psychological support for families of the multiple sclerosis patients (Landoni *et al*, 1999).

These experiences involved dependence- and withdrawal-related dynamics with a possible narcissistic retirement into himself. In the presence of distress the patient puts into action defensive mechanisms to contain it. He resorts to 'projective mechanism', to 'projective identification' or of 'rationalisation'. However, at first the patient puts into action much more the 'denial' that means he is not able to recognise his own real condition. Psychotherapy could then become a favourite setting to control the initial distress and to aid more effective and functional defensive mechanisms into a favourite setting where it is possible to elaborate and to share one's disease-related problems (Crawford and McIvor, 1985; Minden, 1992).

In our experience, the group psychotherapy, with an analytical trend, was made by 10 patients (male and female) with minor disabilities and little cognitive deficit. The psychotherapeutic course was for a term of 1 year. Meetings were weekly for a period of 90 min with a prearranged time and day. The group was led by a psychiatry-psychotherapist doctor with a cotherapist psychologist. A professional nurse of the multiple sclerosis centre was also present. Patients came to the group with a good continuity. The aims of the group psychotherapy were various: to offer to the patients a chance to socialise that they can realise from their experience of the disease; to consider the connected problems in evolution terms of the possibility of mutual support; the discovery of existent resources even if not clear; and the utilisation of healthy dimensions that are present in everyone's life. Our experience shows that the Group can become a setting where it is possible to elaborate developed and healthy defensive modalities as regards 'denial' and 'projective experiences' caused by the distress of the disease. First of all the group had a function of patients' assurances that were expressed by the relational continuity of the meetings; by the essential welcome of the patients and with what everyone wanted to bring into the group. Second, group psychotherapy was also an ambit where we observed spontaneity, empathy and the wish to meet. Patients talked about their disease experiences, their relationship problems (especially in the family), their working experience and their adjustment to difficulties in their own psycho-physical condition. The expressive modality in the meetings showed the progressive development of the Group relations towards the dynamics of mutual support and solidarity. During the psychotherapy course we noticed empathy manifestations, emotional and distress sharing that could find a favourite way of expression, sharing, support and elaboration. The

sharing experiences, the assurance functions and the expressive possibilities that the group gave, all helped the feeling of belonging expressed with a persevering participation, by helping the creation of relations between people even outside the Group meetings and the desire to maintain these references longer.

The onset of multiple sclerosis and its possible relapses change the subjective emotional-affective and relational life of the patient and also have heavy repercussions on other members belonging to the original family (consorts, parents or son) who share with the patient the presence of an important pathological event. The disease can cause changes in the emotive setting of the family, which is why psychological rehabilitation that we mean as psychological support is then important in attempting to restore a harmonic emotive family setting. We observed, as previously described in literature, that at the time of the disease, the quality of families' relations before the disease are very important variables. When the disease is new, relatives address their energies to the patient. If the patient is older, relatives have to review their own projects and their present and future expectations in the same way the patient is doing.

With regard to the quality of families' relations, we observed that when family relations were good before the onset of the disease, the relatives showed a low level of critical and hostile attitude and more consideration for the patient's needs and demands. When there was a difficult relationship the disease became the vehicle to express critical and hostile attitudes. We think that the aim of the psychological support for families of multiple sclerosis patients is above all to help the family to bear the emotional load following on from the disease, so that they do not feel alone in the patient's everyday care and in their own emotional management; to give them a listening space for their distresses and fears; to pay attention and to analyse the observed dynamics, trying to understand them and to read the meaning; to aid the re-establishment of an emotionally balanced family setting where every member has their dignity, their own space, and can express their own needs without forgetting that one of them is ill and so more vulnerable. We carried out the psychological support with the relatives of the multiple sclerosis patients who asked for it by ambulatory psychological interviews fortnightly. Parents can feel ambivalence to the son: the engagement of care compares with the difficulty in accepting that the needs of the ill son become more important than those of relatives. Other parents, on the contrary, express a deep devotion and self-sacrifice showing

the ability to revise the family projects previously made. Consorts can feel sentiments of disappointment, treason and forsaking. Otherwise the ill relative becomes the main beloved to share everyday life with. During the review relatives express their distress about the disease, the uncertainty about the patient's and other family members' futures. At the start they pay more attention to the physical autonomy and to its loss which has repercussions in the social and working setting, then they express their own emotional difficulties and those of the patient. Some relatives expressed difficulties concerning reorganisation of the family dynamics because they were not able to work out the disease and to have a position of project. We noticed then the disposition to minimise possible difficulties (even relational) that the disease caused, and that relatives did not want to consider that some changes took place or that, at least apparently, that there was something to balance again. We could see that several relatives were able to make use of the therapeutic space reserved for them even if only as a place to express their sentiments, uncertainties and fears, and that they considered it as an important reference. We verified that this intervention is very important for the whole family because the disease involves not only the patient but every person who lives near him, who often face this problem alone, unable to find answers or adopt alternative strategies. Relatives need a complete support mechanism to put into action effective defensive mechanisms in order to reduce the pathologic dynamics that sometimes showed which can have a destructive role in the family.

From our experience with group psychotherapy for people with multiple sclerosis, we can conclude that to change patients' psychological points of view is essential in order to offer a listening and a sharing environment for emotions and fears that can be expressed within the group. These can be elaborated in a mutual aid and solidarity context. The group offers the possibility of relations 'between equals', a place where one's difficulties can not only be expressed verbally and understood, but more effectually shared and supported.

Our experience of psychological support for families of multiple sclerosis patients confirmed the importance of changing relatives' attitudes because they are also directly involved in the life difficulties that the disease causes. They also experience distress, fears, guilty feelings and confusion, and can find in the psychological support a good environment of expression, sharing and elaboration.

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