



Training of the relatives of PwMS

REPORT ON TRAINING NEEDS ANALYSIS



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PROJECT BACKGROUND

This Report on Training Needs has been elaborated as a result of one of the main phases of the project QUALIFIED CARE, a European project financed by the European Commission in the framework of the Leonardo da Vinci Programme.

Multiple Sclerosis (MS) is a degenerative disease that causes important disturbances in life of persons suffering it and their families. The physical consequences of this disease causes heavy neurological incapacity in a third of the cases after 5-10 years; another third are considered benign forms that are established and allow to live a normal life, at least during the ten first years of the diseases, and the remaining third evolves in an intermediate way. As the disease evolves, a person with Multiple Sclerosis (PwMS) may need the help of specialized sanitary staff. This would cover part of the time of the patients' care, but in fact families spend more than a 50% of their time on the patients' care. Depending on the level of evolution of the disease, professional knowledge should be required (in fields such as medicine, nourishment, speech therapy, mobility exercises, etc.), because in most of the cases the family members involved in their care have little or no knowledge on this items. Therefore, it is very important that these patients' families have enough knowledge to care and help him/her properly.

For all the above, it was necessary to carry out a project like this, allowing family members of PwMS to acquire the necessary knowledge for helping and caring them professionally.

The main objective of this project has been to cover the lack of training of the relatives of people suffering MS, through the design and elaboration of a training tool specially created for them. In order to know the real situation and background of the relatives of PwMS in the partner countries, an exhaustive analysis was carried out using several research methods: bibliographical analysis, quantitative and qualitative techniques. The results of this analysis are shown in this Report.

The entities participating in the project and in the transnational research have been the following:

- As promoter: Associació Balear d'Esclerosi Multiple – ABDEM (Spain)
- As coordinator: Inveslan (Spain)

- As partners:
 - BMI Association (Czech Republic)
 - Federación Española para la Lucha contra la Esclerosis Múltiple – FELEM (Spain) www.esclerosismultiple.com
 - Fundación Esclerosis Múltiple Eugenia Epalza (Spain) www.emfundazioa.org
 - Greek Multiple Sclerosis Society (Greece)
 - Hellenic Regional Development Centre – HRDC (Greece)
 - Pragma Engineering Srl. (Italy)

More information about the project QUALIFIED CARE can be found in the website:

www.qualifiedcare.net

A. DOCUMENTARY ANALYSIS

1. INTRODUCTION ON MULTIPLE SCLEROSIS

Multiple Sclerosis (MS) is a long-term disease that affects the central nervous system, formed by the brain, spinal cord and the optic nerves. It is the result of damage to the myelin, as when it is damaged, it interferes the messages between the brain and other parts of the body. This disease is a very variable condition and the symptoms depend on what areas of the central nervous system have been affected. There is no set pattern and the symptoms vary time to time and can change in severity and duration, even in the same person. MS is a dynamic disease, with almost constant lesion formation and a progressive clinical course leading to physical disability.

With the advent of Magnetic Resonance Imaging (MRI), the ability to confirm the diagnosis of MS has dramatically improved. Newer MRI techniques (eg, magnetization transfer, fluid attenuated inversion recovery or FLAIR, and MR spectroscopy) promise to yield important information regarding MS heterogeneity, prognosis and treatment effects.

The disease can be presumably exacerbated by hormonal changes during the postpartum period. Some argue that MS could be a heterogeneous disorder triggered by several different environmental agents. In fact, only 1 in every 4 MS attacks is associated with a viral infection. Genetic susceptibility factors may play a role, as the disease is more common in Caucasian populations living in northern latitudes. In the US MS has a prevalence of nearly 350,000 cases in the US alone. Every year, approximately 10,000 new patients are diagnosed with MS. More than 1 million worldwide are affected.

MS causes considerable disability in the working age population group. People with MS usually die of other complications, including recurrent infections (especially in bedridden patients). MS patients may have a life expectancy reduced by 7 years, as compared to the general population.

MS presents more often in populations of northern European ancestry. Whether disease severity may also be accounted for by racial differences, is controversial. The concordance rate for MS is 20-40% among monozygotic twins, suggesting the presence of predisposing genetic factors of non-Mendelian inheritance. In addition, migration to high risk areas before age 15 years is known to increase the risk of developing MS, lending further support to the environmental

factor hypothesis.

MS affects females more than males (1.6-2:1), but the basis for this difference is unknown. This ratio is even higher (3:1) among patients with the onset of MS earlier than age 15 years or older than 50 years, suggesting a hormonal component to the disease process. Males have a higher tendency to develop primary progressive MS, while females tend to experience more relapses. MS most commonly afflicts people between the ages of 18-50 years, but any age group can be affected.

The disease can present in different forms, such as primary progressive, relapsing remitting, relapsing progressive and secondary progressive phenotypes.

Bone densitometry studies are indicated for MS patients who have received long-term corticosteroid treatment or are at higher osteoporosis risk from menopause or chronic immobility.

Additionally, patients who have progressed beyond EDSS disability scale scores of 5.5-6 tend to respond poorly to the current treatments.

The impact of disease in the quality of life is reflected in the high suicide rate (7.5 times higher in MS patients as compared to the general population). However, as stated above, reactive depression by itself does not fully account for this higher suicide incidence. It is believed that the accumulation of lesions in the brain eventually has an impact on mood level.

Thus, preventing disease progression by using available medications is imperative in MS treatment, especially for patients who have been diagnosed early and will probably respond to treatment.

Interferon-beta-1b was shown in a 2-year, double-blind, placebo-controlled trial of 372 relapsing-remitting patients to decrease the frequency of relapses from 1.27/year to 0.84/year, a 34% reduction in the relapse rate compared to placebo. Five year follow up data reports that disease progression was 35% in the interferon-beta-1b group and 46% in the placebo group. A 30% decrease in the yearly exacerbation rate in the treated group over five years was also

demonstrated. While the placebo group had a median MRI lesion burden of 30.2% over five years, no significant increase (3.6%) was detected in the interferon-beta-1b treated patients. Interferon-beta-1b is of benefit in delaying disability in early secondary progressive MS.

Caution in pre-existing seizure disorder. Cases of exacerbation of thyroid dysfunction have been described; caution when using interferon beta-1a in patients with uncontrolled thyroid dysfunction; besides, a flu-like illness, patients may experience injection-site skin reactions which may range from mild (slight erythema) to severe (skin necrosis); interferons are abortifacient; data on teratogenicity are limited; extreme caution in patients with severe depression.

Interferon-beta-1a was studied in a double-blind placebo-controlled study in 301 relapsing remitting patients receiving weekly intramuscular injections of 6 million units (30 micrograms). Over two years the annual exacerbation rate was 0.90 in the placebo group and 0.61 in the interferon-treated group, a 29% reduction in the relapse rate. At two years an MRI lesion volume of 122.4 (mean) in the placebo group was found, compared with 74.1 (mean) in the interferon - treated group. The number of MRI enhancing lesions over two years was 1.65 (mean) in the placebo group and 0.80 (mean) in the interferon -treated group. By the end of 104 weeks, the proportion of patients progressing was 34.9% in the placebo group and 21.9% in the interferon group. Also, 22% of patients on treatment developed neutralizing antibodies. Recent results suggest that interferon may help delay the development of brain atrophy and cognitive decline in MS patients, but more long-term data is needed to assess how significant is its clinical impact to patients.

Interferon-beta-1a has been shown to delay the onset of disease (recurrent attacks) if administered to patients after an isolated demyelination event (results of CHAMPS and ETOMS trials recently completed). There is considerable controversy at present as to whether the delay in the onset of new attacks ultimately has an impact on neurodegeneration and disability; these issues will need to be addressed in future trials.

Glatiramer Acetate (Copaxone) showed positive effects in a large double-blind trial in RR disease involving 251 randomized patients. Patients on Copaxone had a 2-year relapse rate of 1.19, while patients on placebo had a rate of 1.68. The relapse rate reduction was 29% over 2

years for patients on Copaxone. Extension data shows that over 140 weeks, 21.6% of Copaxone treated patients worsened, as compared to worsening of 41% of placebo patients.

Recent results of an 18-month study examining the impact of Copaxone on MRI outcome show a 35% reduction in the number of new T2 lesions.

There is no currently available highly effective treatment to counteract MS attacks. The most widely used treatment is IV methylprednisolone, 1 g IV qd for 3-5 days. This medication may help expedite the timing of recovery but will not affect the actual degree of recovery. High dose IV steroids may work more effectively than oral steroids for the acute attack, and it is recommended that home IV therapy be instituted if the patient does not require hospitalization. Alternatively, high dose oral methylprednisolone should be used, when feasible.

The patients with secondary progressive may be treated with interferon, especially when the clinical course reflects an early (EDSS under 6) phase of progression. Interferon is also effective for relapsing remitting MS. Mitoxantrone is approved in North America and Europe for use in MS patients. Patients on Mitoxantrone need to be monitored with echocardiograms or MUGA scans prior to and during treatment, as there is a risk of cardiomyopathy. There is no study yet comparing the efficacy of mitoxantrone and cyclophosphamide in large numbers of patients. When studied individually, mitoxantrone seems effective for all ages tested. The data on Cytoxan, in contrast, indicates that this drug may be more helpful to male patients under age 40 years. Controversy exists whether patients with dramatic and rapid progression of disease (regardless of the type and timing of MS) should be treated or not with immunosuppressive agents, to try and arrest the ongoing inflammatory cascade. Azathioprine and Methotrexate may also be used as immunosuppressive treatments for MS, but these drugs should not substitute the ABC treatments as first line agents in newly diagnosed relapsing remitting patients. They are considered less suppressive than mitoxantrone or cyclophosphamide, and are increasingly being considered as combination partners for the ABC drugs.

Surgical procedures that concern MS are primarily directed to help alleviate symptoms such as dysphagia, significant limb spasticity or contractures, or severe neuropathic pain. Measures include gastrojejunal tube placement, adductor leg muscle tendon release, and rhizotomy,

respectively. Intrathecal pumps for delivery of antispasticity medications (eg, Baclofen) can be surgically implanted. Penile prostheses are an alternative to patients with erectile dysfunction who do not respond to medical management.

Due to the disseminated CNS involvement, patients with MS may require multiple consultations to rule out other causes for their symptoms. Evaluation by an otolaryngologist (ENT specialist) to rule out laryngeal lesions unrelated to MS. In addition, having MS does not exclude the possibility of concomitant peripheral neuropathy or other illnesses that may cause pain. Listed below is the range of most common consultant services involved in referrals from an MS clinic. Gastric tube (G-tube) placement for feeding in advanced cases is an example. Urologic consultation might be warranted to help assess and treat incontinence. Neuropsychological evaluation, especially in patients with primary cognitive involvement, is advisable so that a baseline assessment for future reference can be obtained.

There are no specific dietary restrictions that apply to MS; patients are encouraged to eat a balanced diet. Oral intake of calcium and multivitamin supplements are encouraged as adequate vitamin D sources.

Patients are encouraged to exercise regularly. Strenuous exercise and excessive exposure to heat and or physical exhaustion should probably be avoided; however, there are no studies that have comprehensively addressed this issue in MS patients. MS patients should avoid exposure to hot showers or saunas, as increased body temperature has been associated with MS exacerbations.

In short, the symptoms commonly affected by the MS include the following: visual disturbances, balance and coordination problems, spasticity, altered sensation, abnormal speech, fatigue, bladder and bowel problems, sexuality and intimacy problems, sensitivity to heat and cognitive and emotional disturbances.

As explained above, it can have different effects on patients and their families, but it normally causes important disturbances on the way of life both of people suffering it and of those living with them, due to the increasing level of disability and symptoms experienced by many patients

that affect working, family and social life. But MS is one of the most difficult conditions to forecast, and the sense of uncertainty is usually a serious problem for the patients and their families.

Since there is not a healing treatment for MS, one of the main objectives for fighting against this disease, besides the palliative treatment with medicines, is to improve life quality of the affected persons, through the labour, social and family environment.

As the disease evolves, the collective of affected people needs the help of specialized sanitary staff. This one covers only a part of the time devoted to patients' care, being their families who have to spend the most of their time caring for them. In this case, families sometimes cover more than 50% of time of the patients' care, depending on the level of evolution of the disease, and in most of the cases, the family members involved at this collective's care do not have any knowledge at all, and if they have it the reason is that they have acquired it in a non-formal way.

Therefore, it is very important that these patients' families have enough knowledge that allow them to care and help the MS patients, completing the time the sanitary staff does not cover.

Thus, this is the main basis for the creation of the project QUALIFIED CARE: to allow family members of MS patients to get the necessary knowledge for helping and looking after those patients in a professional way. The main aim of this Report is to analyse the Training Needs of people who take care of patients with MS, thinking about the causes that difficult the acquisition of knowledge in this field.

As the project is being performed by partner entities from different European countries, this Report describes the situation of the relatives of people suffering Multiple Sclerosis in each country, the support they get for looking after the patient and their background for these tasks.

2. DOCUMENTARY ANALYSIS IN CZECH REPUBLIC

2.1. Relatives of people suffering MS. Their role.

Currently, there are about 10.000 people with MS in the Czech Republic. Only a few hundreds of them are immobile and need help of other person or a wheelchair.

Multiple sclerosis has a significant negative influence on the whole family, which has to adapt to this disease and its impacts. Partners often hardly deal with this new situation, they can be even under the stronger press than the patient himself in the case that they decide "to go or to stay". When the partner relation is primarily not good, MS is often called the cause of all emotional, partner and sexual problems. This can result in separation or divorce, especially when the MS patient is a woman.

Aggressiveness is a common problem in relationships of people with MS, being expressed either directly or indirectly. Patients are often unable to express the feelings of anger, especially when they are fully dependent on their partner and they are afraid of rejection, or if their healthy partner feels guilty. This may end up in a lack of sincerity between the partners, manipulations and "playing games".

Uncertain person with MS can get to the role of dependency that further produces negative feelings, such as hate and anger. The relative can compensate his/her own wish to refuse the role of caring person by aggressive and hyperactive behavior.

Also children can draw attention in a non-adequate way when their needs are not being fulfilled; they must be informed about MS with respect to their age. Feelings of exclusion may cause gloom and sadness of children. When the family problems continue, then a help of specialist, e.g. psychiatrist is needed.

Relatives of persons with MS caring of them have to acquire a not only sensitive but also stable attitude to these people. It is necessary that professionals and volunteers were well-trained, supported and controlled.

Doctors must ensure that all family members understand that the disease itself may cause problems in concentration, memory, expression of emotions and self-control to the patient. It is often hard to admit whether the emotional and behavior symptoms are direct signs of MS or they are only a reaction to difficult putting up with the disease and its consequences.

Every phase of this disease is difficult for the patients and brings specific problems that need to be solved. In the first phase, this help consists mostly of giving information, psychological intervention and prevention of specific symptoms, while in the second and third phase it consists mostly of direct treatment of specific symptoms, and in the fourth one, of keeping the self-reliance in doing common daily activities and social support. Each of these phases should include specific support that help to improve the quality of life of both patients and their relatives.

Unfortunately, there is no systematic support of relatives of people with MS in the form of providing knowledge in the Czech Republic, training and psychological support yet, nor exists any complete system of care of patients with MS.

In the Czech Republic, there are 9 Centers for MS that ensure well-timed, specialized diagnosis and treatment. However, there is still low awareness of patients about MS, insufficient communication among individual specialists (for example among neurologist, urologist, surgeon, gynecologist, dentist), and non-coordinated care of patients by all specialists (psychologist, psychotherapist, physiotherapist, speech therapists, ergotherapist, social worker, etc.). Problems are often solved too late and not efficiently enough and the symptoms of the disease are treated only through medicaments, so there is no prevention. Services as rehabilitation, psychological intervention or social consultation are often offered very late, when the problems of patients are already enormous. The MS centers above are focused only on patients themselves, without including support of their relatives.

MS always comes unexpectedly into the life of people and they have to adapt to the new situation. They are afraid that it will change the relationships with the family relatives, that they will have problems at work and in every day life, lose their independence. On the other hand, there are relatives and friends of the patient, as for them it is a big change too, even they have to change a lot their life. The whole family is mostly touched with feelings of anxiety and fear about

the loved person. It all depends on the process and seriousness of the disease, and also on the family structure and partner relationships. The life of family has to be adapted. Person with MS is often tired, less efficient and partner has to take on part of his/her every day tasks. When the patient has a problem on the locomotive organs (temporarily or permanently), he/she needs help even with the personal hygiene. It is important that patients talk about their difficulties, feelings, fears and wishes. They should not exert themselves too much and should allow the relatives to help them when it is needed.

The role of relatives taking care of people with MS depends on the extent of the disease. At the beginning, it is necessary to take on part of the housekeeping or following on travel outside home. Care of less disabled persons includes shopping (food and other things), cooking, housekeeping, care of children, following patient to the doctor etc. In the hardest cases, it comprises complete care – hygiene, feeding, moving, etc.

2.2. Support and help the relatives receive for the care of the person with MS.

There are many possibilities to get support for persons with MS themselves. Persons with disability caused by MS may ask for economic support from the government. This support is provided by Ministry of Education, Youth and Sports, which provides social benefits for people with disabilities. These benefits are the following:

- Contribution for adaptation of flat: for people with hard defects of locomotive organs and blind people to remove the barriers in their flat. The amount of benefit can be at most 75% of proved costs, but not more than 50.000 CZK (1.670 €).
- Contribution for individual travel: for people with hard defects of locomotive organs and blind people, who do not own a motor vehicle. The amount of benefit is 6.000 CZK (200 €) per year.
- Contribution for buying an own motor vehicle: for people with hard defects of locomotive organs, blind or mentally disabled people. The amount of benefit is up to 100.000 CZK (3.300 €).
- Contribution for complete overhaul of motor vehicle: for people with hard defects of locomotive organs, blind or mentally disabled people. The amount of benefit is up to 60.000 CZK (2.000 €).
- Contribution for adaptation of motor vehicle: for people with hard defects of locomotive organs, who drive a motor vehicle and need this adjustment because of their disability (fully covered).
- Contribution for using a motor vehicle: for people with hard defects of locomotive organs. The amount of benefit is up to 9.124 CZK (300 €).

There are also monthly benefits:

- Contribution for using a non-barrier flat: for people with hard defects of locomotive organs. The amount of benefit is up to 400 CZK (13 €) per month.
- Contribution for higher life costs: for persons using orthopedics, compensating or other facilitating instruments. The amount of benefit is up to 200 CZK (7 €) per month.

- Contribution for using a telephone: for people with disabilities. The amount of benefit is up full cost of basic monthly lump sum.
- Contribution for using a garage: for people with disabilities.

There are also extraordinary benefits for people with hard defects of locomotive organs disabilities. They are divided into 3 degrees: TP, ZTP and ZTP/P.

There is also a possibility of free of charge loan for people with disabilities who are in a bad life situation that can be overcome with this loan. The amount of the loan is at most 20.000 CZK (670 €). In the case that person with disability fulfills the condition for benefit for buying a motor vehicle, it is possible to provide the free of charge loan up to 40.000 CZK (1.340 €). This benefit is provided by municipality.

Other different benefits are the following:

- Contribution for city travel costs: for participants in recreation and bath care, up to real costs.
- Contribution for buying special facilities: for people with hard disabilities. The amount is set in a percentage sum of the price of the facility.
- Contribution for persons, who are placed in the institute of social care.

There is no goal-directed provision of **psychological support** for relatives of MS patients. It can be requested in health services, but it is difficult to find a psychologist specialized in this issue. Otherwise, relatives can only visit a general psychologist found by them. It is also possible to look for help within the scope of private organizations working in the field of supporting people with MS. The most important of them is Union Roska. It is a civic organization helping people with MS, and it has branches in all 14 regions, with more than 2500 members. Other organizations where help may be requested can be the church diaconies, for instance.

Similar situation happens concerning the **health support**. Health support for relatives of persons with MS is not goal-directly provided. It is also possible to ask for help in private organizations that take care of people with MS.

There are also domiciliary services for the delivery of food available for relatives of people with MS. But generally, support of these caring people is minimal in the Czech Republic. They often lose even their own job.

2.3. Entities offering the relatives support for the care tasks.

When patients with MS stay at home with a family that keeps attention to them and follow the advice of the neurologists, the illness can be stabilized or the condition even improves due to good mental condition. Therefore the role of the family members taking care of the patient is very important. However, there is not sufficient support of these relatives yet. There is only a number of institutions, both public and private, taking care of patients with MS. In many of them, relatives can find information and help in case of troubles.

There are the following 9 MS centers in the Czech Republic, state supervised and functional in cooperation with neurological institutes:

- . Neurologická klinika -Fakultní nemocnice Královské Vinohrady,
- . Neurologická klinika 1. LF UK - Všeobecná fakultní nemocnice Praha2,
- . Neurologická klinika Fakultní nemocnice Motol Praha 5,
- . Neurologická klinika Fakultní nemocnice Hradec Králové
- . Neurologická klinika Fakultní nemocnice Plzeň
- . Neurologická klinika Fakultní nemocnice Bohunice, Brno
- . Neurologická klinika Fakultní nemocnice Olomouc
- . Neurologické oddělení FNsP Ostrava-Poruba
- . Nefakultní regionální centrum se supervizí Centrem v Olomouci
- . Neurologické oddělení Baťovy nemocnice
- . Neurologické oddělení Krajská nemocnice Pardubice

These centers were created with the following aims:

- To ensure the expert diagnosis and treatment of MS and other demyelinic diseases.
- To ensure the treatment and specific treatment approaches, that require continuous immunological and electrophysiological monitoring.
- To ensure the complex treatment, part of which is a specialized neuro-rehabilitation

- To ensure the training (on pre-graduate and post-graduate level) in the field of demyelinating diseases, including the creation of continuous training scheme.
- To carry out research and development activities in the field.
- To enhance the cooperation between Czech and international centers in this field.

Besides state-supervised centers, there are some organizations, associations and other institutions where help can be sought. These centers are not oriented solely on the physiological side of the disease, but also try to tackle the disease in its entirety, taking into consideration psychological and family aspects of the disease.

One of the private organizations dealing with the problems of the MS is the above mentioned **Union Roska**. As a Czech MS organization, Union Roska is an active member of the international federation MSIF and its European platform EMPS (working under the auspices/supported by the EU/...) with a nationwide impact. The following programmes can be found amongst its activities:

- Running of the MS center ROSKA in Prague-Holesovice.
- Exhaustive information service.
- Publishing of books, audio rehabilitation audio and video tapes in the ROSKA edition.
- Issuing a periodical with a nationwide distribution "Roska", publishing the information newsletter Roska Plus and other educational brochures and regional print.
- Educational activities: teachers' training at its own accredited educational work station, as well as execution of vocational training courses and seminars.
- Social and employment law consultancy.
- Conferences and exhibitions.
- Implementation of health-recovering events, such as re-conditioning and rehabilitation stays (in Czech Republic as well as abroad).
- Active cooperation with doctors/physicians.
- International cooperation.
- Club activities.

This extensive activity is not limited to the members of Union Roska; the programmes are open to all those affected by the MS.

An irreplaceable institution providing care for MS patients is the **Home of St. Joseph**. This place with home atmosphere and expert health care is an asylum for MS patients, giving them a chance to live a full and active life with dignity.

Home of St. Joseph is a privately-owned health facility providing conditions for dignified life to patients with MS, through the provision of a complex care, as well as other supporting services, such as counseling service on home care and MS and aid rental for disabled. Home of St. Joseph is the first and only example of facility with complex care of patients with MS. It is located in the baroque monastery with the castle garden in Žireč u Dvora Králové n. L., and its activity began in December 2001. The basic principle of its work lies in understanding of singularity and respecting the personality of a patient. The activities include the following:

- Health and social care;
- Rehabilitation, relaxation and aroma therapy;
- Psychotherapy and duchovní péči;
- Art therapy, music therapy, and ergo therapy (therapy using art and creativity) ;
- Cultural, educational and leisure time activities including educational trips;
- Long-term dialogue with the representatives of state and municipalities, legislative authorities and insurance companies in regards of the benefits of the patients;
- Active engagement of general public through volunteer work on the organization of cultural and educational events, as well as voluntary financial help.

The Home has three departments:

- Department of permanent stay: for MS patients, who lack the functional family background and are dependent on others' help.
- Department of nursing beds: the stay lasts a maximum of 2 months, and the emphasis is put on rehabilitation and training of self-sufficiency;

- Departments of short-term stay: the stays last 1-3 weeks for patients in home care, whose caring family needs a short period for regaining strengths for further care, as its a prerequisite for good relations with the patient and among the family members;
- Rehabilitation center: equipped with a gym with necessary equipment and tools, bath tubs for water cure (different types), and equipment for walk training.

Besides the nursing care, the Home tries to support the development of home care and so make it possible for patients to stay in home environment as long as possible. Therefore, the Home provides:

- rental service of supportive and therapeutic instruments for ill and their home nurses,
- counseling service for home nursing care.

Another institution offering help for MS patients and their relatives is a civic organization **CEROS**, the center of complex neuro-rehabilitation care for patients with MS.

The aim of the CEROS center is to provide complex, early and lasting cerebral-spinal treatment as a means of symptom reduction and slowing down the progress of the disease in order to improve the life of the patients, their families and friends.

The concept of goal-directed approach to the patient includes:

- development of theoretical analysis,
- experimental verification of hypotheses,
- multidisciplinary experts discussion at national and international level,
- formation of expert teams dealing closely with the problems and training of new experts in the field,
- preparation of arguments for dealing with the health insurance procedures,
- gathering support of the professional organizations.

The company keeps activities leading to the creation of "the Centre", a hierarchical system of work places, which would, at national level, provide early, continuous, specific and complex care.

CEROS has developed the following projects:

- "Multiple Sclerosis in a Net" which offers, in cooperation with a number of current MS institutions, the network of complex services for those affected with MS, ranging from Physiotherapy, Ergo therapy, Cognitive Rehabilitation, Uro-rehabilitation, Speech therapy, Psychotherapy, Dance Therapy, Music therapy, Art therapy, Hippo therapy to reconditioning activities, seminars, workshops and Employment Law counseling. Furthermore, there are activities aimed at the popularization of the MS problems with the goal of making the patients feel better in the society.

- "Road to the Rainbow", with the exhibition of works of MS patients:
 - media campaign on MS and the vision of CEROS,
 - public (money) gathering.

- Project "Urologic problems accompanying the MS (cerebro-spinal) - the impact of shame and public opinion".

The civil organization **Orfeus** addresses the disabled people in general. With its primary goal to reach the equality of disabled persons and parents of disabled children in society, the association carries out the following activities:

- application of rules set by the UN's General Assembly to ensure equal opportunities of disabled persons,
- active participation in the development and amendments of provisions influencing lives of disabled persons,
- socio-legal advisory office for disabled persons,
- organization of educational activities for disabled persons, including re-qualification courses (vocational),
- organization of events focused on culture, sports, arts and others,
- publication of information and other documents relative to disabled citizens, including the advice on legal position of disabled in the society,
- mediation for the purchase of technical equipment enabling the compensation of the consequences of disability on the opportunities in social life,
- provision of social intervention services,

- provision of social care services,
- provision of individual help to the disabled persons,
- provision of other activities helping the disabled persons.

During the fulfillment of its mission, Orfeus cooperates with the bodies of the state sector, municipalities, as well as legal and natural persons in Czech Republic and abroad.

Furthermore, there is a civil organization called "**Creative Workshops**" offering services to the young disabled persons and helping them with employment and integration issues.

This association provides:

- The center of daily service: daily programmes focused on employment and integration support. The target group is formed by students and graduates of special schools with severe physical disabilities.
- Individual counseling in the field of employment of physically disabled people: it provides information about the options of their employment on the labour market. The target group is formed by organizations, potential employers of disabled.
- Mediation of contacts with other services, even of non social nature supporting the employment and integration of disabled people. Target group is divided into two: the primary one is formed by young people with disabilities, their family and relatives; the secondary one by service providers.
- Regular group supervision, through the so-called "Balin groups". The target group is formed by workers of supporting fields and their support.

The **Domov Sue Ryder, o.p.s**, is an independent facility, providing and ensuring social and medical service to the needy citizens. Within its activities, the organization provides the following services: temporary, long-term and permanent stays for needy citizens (seniors, disabled); social and nursing care in the customer's homes; day care treatment facility for seniors, ergo therapy, personal assistance, preparation and sale of food to the customers.

The **Civic organization DAGDA** was created with the aim of establishing and running therapeutical, residential, educational and cultural center. Its mission is the educational and

dissemination activity in the field of disabled people's problems, and the help of their integration to the society. The main activity of the Centre is the organization of educational, therapeutic stays of handicapped and their families and tutors, in connection with artistic and educational activities.

The mission of the Centre within its educational goal is the organization of courses in the field of healthy life-style, which should create a place for gathering the information and knowledge leading to reaching the balance and health in one's life. The mission of the Centre within the field of culture is the organization of arts symposia, creativity workshops for students of art schools, supporting projects in visual arts, music, theatre, dance, documentary photography and film, and organization of art exhibitions and publishing of catalogues and publications.

The **League for the Wheelchairs Rights** is an organization devoted to the work with physically disabled people, mainly with those on wheelchairs. The activities run are aimed at helping and making the everyday problems of people on wheelchair easier. Among the main activities belongs the publishing of the *Vozičkář* magazine, which is being published 6 times a year in 5000 copies. The part of the magazine is, among others, a socio-legal advisory office, sexological counseling...

The barrier-free **theater BARKA**, where it wishes to create conditions for either passive or active engagement of people with different types of disabilities, as well as create a space where activities for both disabled and without it is possible and is thus a natural way of integration. Organization is also the co-organizer of nationwide presentation of non-governmental non-profit organizations with humanitarian orientation called "For Your Smile", which takes place annually at Brněnské výstaviště together with MEFA and REHAPROTEX events.

The important part of their activities are the health-oriented sports therapies and reconditioning residential events, intended for youth and people in active age.

Nadatio SAMARITANUS provides health and social help for disabled, i.e.: home care, the center of health and social help and others.

It also organizes cultural events for physically and mentally disabled, psychological advisory office, transport of immobile patients, day care treatment facility, including protected workshops for disabled, bookbinding and sewing workshops, compensation tools rental, reconditioning swimming and rehabilitations.

Association of Friends of Konto Bariéry. The aim of this association is to offer a humanitarian help to disabled people, to those in need or in other difficult life situation, through Konto Bariéry. In cooperation with Chart 77, Association published a magazine Bariéry and newspaper Můžeš (You can).

The magazine Bariéry addresses the values of civil society, the work of philanthropic foundations, civil associations and groups.

In its extensive information campaign, (the magazine) introduces all big foundations in Czech Republic, their scope of influence and their grant programmes. Its publicity pages map the activities of volunteers associations and groups that are active in municipal affairs and urban events; part of the magazine is dedicated to students of Social Studies majors and their opinions and observations. The Magazine is distributed among the members of Parliament, Senators, Ministers, employees of Ministries, Municipal offices, influential persons (VIP's), media, political parties and of course (philanthropic) foundations, associations and other non-profit organizations in the regions of Czech Republic.

The newspaper Muzes (in English "You can") is published for nine years with the aim of spreading information to people with disabilities, mainly because lack of information is largely observed by this group. Therefore, this newspaper tries to map the happening in the health service field, in social and economic affairs, it writes about rehabilitation opportunities, new treatments and drugs, methods and equipment. It also brings encouragement, positive stories and examples. The newspaper is being published in 5000 copies, out of which 1000 copies is distributed to a variable set of addressees (depending on the information in each issue) and the other 4000 copies are distributed to subscribers (organizations and clubs of disabled, ie: oncology patients, epileptics etc., rehabilitation and recovery centers and institutes, sanatoria, associations and agencies helping the disabled, disabled themselves and their families...). Given its scope of

interest, the newspaper Muzes ranks one of the top periodicals with the largest number of disabled readers.

Civic organization Sunrise operates as beneficial organization with a nationwide working sphere. Through its activities, it enlarges the supply of rehabilitation methods for disabled and variegates their life through yet another activities, going beyond the traditional framework of recondition activities of disabled. Hiporehabilitation is a treatment procedure that certainly has its place within the complex of rehabilitation. The Association operates the ambulatory hipotherapy service, organizes holiday stays for children each year bound together with the hiporehabilitation and complemented with other rehabilitation and reconditioning children's activities, additionally, one-time events (welcome of spring, etc.). The reason for these events is to give families with disabled children the opportunity to meet and socialize, get to know other families and compare and share the experience with care of disabled child. The existence and activities are provided with the help of volunteers, taking care of everyday association's tasks as well as assistant work; the expert supervision of rehabilitation and horse preparation is carried by the Association's employees.

Pražská Organizace Vozíčkářů, the civic organization, which is engaged in pursuit of justified interests and requirements of disabled people, mainly those on wheelchair and within these borders, the issues of social security, legislation, rehabilitation and compensation tools, technical and social barriers, transport, living and employment.

Within its activities, the organization tries to create desirable conditions for satisfaction of individual health, social and working needs of physically disabled people. It provides and organizes these services and activities: courses of social rehabilitation, personal assistance, counseling and facilitating activities, leisure activities (sports, culture, social events), establishing contact with foreign subjects.

In Brno, there is, for example:

The Centre of recondition, rehabilitation and re-socialization - C3R, ops. It was created as a reaction to the ongoing arguments in financing the prevention of cardiovascular diseases

campaign, oncological diseases and disorders of locomotion organs. Its activities are focused on primary prevention (seminars, courses, publications for the overall recovery of healthy life-style) and on tertiary prevention (to avoid the social consequences of disease already overcome).

Alongside the education and publication activities, the organization runs the rehabilitation and reconditioning center.

In Jihlava, there is, for example, a non-profit organization called **Tyflo Vysočina**, offering an assistant service, compensation tools service, help in barrier elimination, day care treatment facility, leisure activities, training and recondition activities, and publishing of own regional magazine.

Besides **Tyflo Vysočina**, there is an **association LIFE 90**, specializing in the cooperation with seniors and disabled living in Vysočina region. This association implemented the following projects:

- Emergency care AREÍON - watchdog and security system for seniors and disabled.
- Personal Assistance - help to clients with severe health problems.
- Infophone - information source for seniors and disabled.

The membership in this association is free of charge and currently has 350 regular members, for whom the social events are organized. A part of association's work is the publishing of ZIVOTNIK magazine.

In Roundice nad Labem, there is the **Humanitarian Association Perspective**, which implements project focusing on disabled fellow citizens in Roundnice nad Labem and its surroundings. For its purposes, a daily social service center had been established in Havlickova street. The Association tries to use multi-source financing for its non-profit activities, using state endowments, regional municipality endowments, as well as grants, financial gifts of sponsors and other gifts.

Not a small part of care provision for patients affected by MS is delivered by church organizations, which are following:

In Brno, the **občanské sdružení Betanie - Christian help**. Betanie is civil organization with a separate legal subjectivity and is legally acknowledged as private-owned health facility. It helps people in need, in difficult life situations and mainly the elder.

Its charitable activities are composed of:

- Day care at client's homes - help according to client's specific needs, they try to establish personal relationships, they help with problem-solving and tackling the feelings of loneliness.
- Nursing care (nursing of a patient at home according to the doctor's recommendation) – they enable patients to stay at home instead of going to the hospital to reach the lethal phase.
- Counseling services - physician, lawyer and psychologist help to solve personal, family and interpersonal problems, free of charge.
- Social counseling - help to set up a claim to receive ie. pensions, ZTP.
- Helping the blind - guide and read aloud service, teaching the spatial orientation.
- Training activities: they train nurses, women managers, NZP, graduates of social and family schools for nursing at home.
- Participation in humanitarian actions (campaigns) for refugees, displaced, countries in or in post-war state, reconditioning stays and holiday camps (for disabled, reconditioning stays during the year for disabled and seriously ill fellow citizens in rehabilitation programme).

Diacony of the Evangelical Church of Czech Brethren in Rýmařov is devoted to the care of seriously ill patients, consults with medical practitioners, administers the documentation and forwards information, also engages in care of patients with colostomy, trains in self-sufficiency,

administration of medicine and more. Nursing care is delivered in the form of new nursing process. Carries out the individual care, reaching the level of basic methods of social and nursing forms of cooperation with clients. Nursing care helps the family to manage taking care of their family members at homes, as well. Medical treatments are fully covered by the health insurance.

Diacony of the Evangelical Church of Czech Brethren in Litoměřice provides counseling and information on rights and justified claims for persons in difficult life situations. The Club of Diacony ECCB is a barrier-less facility offering a nice sit-down at the club coffee shop and in the afternoon hours, also internet services and PC usage for public, as well as leisure time activities.

Social counseling is designed for those who are looking for help in setting up claims to enforce rights, in communication or usage of public space and service. It offers counseling service, information retrieval on rights and justified claims, representation and accompanying. While solving a specific problem, they cooperate closely with competent institutions and authorities.

Social counseling includes:

- single or repetitive individual discussions in the re-socialization framework of the client,
- crisis intervention - problem solving in cooperation with competent authorities,
- provision of needs such as assistant care for external clients; minibus transport, etc.

Some cases require long-term and more complex help; others need one-time help. In crisis intervention, there is a possibility to use the pastoral care of the Center's person. It is always its goal to solve the situation in its complexity with the cooperation of professional and competent institutions and authorities. They cooperate very closely with state authorities and municipalities as well as with other Churches.

This is not an exhaustive list of all medical facilities, associations, organizations that work in the field of care for MS patients. However, it can be said that in each and every region there is a medical facility and non-profit organization, which operate for the benefits of MS patients (these are mainly the regional branches of Unie Roska).

Furthermore, there are many web pages supplying practical general and expert information about the disease (MS) and available alternatives in treatment, care, and on cooperation among affected and their families. Few examples:

- www.krizovatka.cz

Has " the search not only for disabled" in its subtitle. This web page specializes in supplying the overall know-how for disabled - whether in health, social or law fields.

- www.heplpnet.cz

Is an information portal for people with specific needs, and it also deals with MS problems.

- www.infoposel.cz

Is designed for disabled in general, there is a social and psychological advisory board.

- www.internetporadna.cz

Advisory, information and discussion server for people with specific needs, their families and friends.

- www.ereska.cz

Information and discussion server of Mrs. Sibrinová, who is herself affected by MS and, through this server, tries to help and inform about this disease, on its course and treatment alternatives. With the help of this server, not only patients can communicate and exchange tips and experience with the disease.

- www.homohumanus.cz

Czech server of home and nursing service care.

- www.prvnikrok.cz

It is the portal dealing with the problems of disabilities There is a database of rehabilitation exercise for patients with MS, as well as their detailed description with photographs.

The care for disabled persons is about to change in the nearest future in the Czech Republic. The Ministry of work and social affairs plans the creation of a system of integrated rehabilitation, which will allow for rehabilitation to be more complex, more effective and better coordinated than ever before.

The basic thesis of this system had been discussed by the government. The main problem is seen to be the current legislation not allowing mutual links and cooperation of each rehabilitation area. The decision making on the best method of rehabilitation for a patient is rather chaotic and the solution is thus many times unsatisfactory and inadequate. What is lacking is mainly the link between the physical rehabilitation, improving the physical condition, and other areas. These other areas are social rehabilitation, integrating the patient to the society, pedagogical rehabilitation, securing the adequate education, and work rehabilitation, helping the patient to find a proper work commitment.

With the support of Ministry of health of Czech Republic and Nadační fond impulse, a training video tape has been produced, containing a set of activities and elements of neuro-rehabilitation for MS patients, in order to forward the information on proper physical activities to MS patients and to provide the specialists with the framework for recommending the proper physical activity to each patient specifically.

In practice, we can see that there is often a certain physical activity being recommended to a patient, without actually explaining the patient the principle in which the activity will help to improve their condition. Therefore, the patients exercise without understanding which can lead even to a self-damaging exercise. The aim of the video-tape is to really show the importance of proper physical activity being a part of life, not only of MS patients but people in general. With MS patients the exercise has its specifics and can lead to an enormous improvement in the patient's condition.

The authors of the contents of the video-tape are PhDr. Kamila Řasová, ing. Jan Vrána, doc. MUDr. František Véle, CSc., doc. MUDr. Petr Brandejský, CSc., doc. PhDr. Anna Hogenová, doc. PaedDr. Pavel Kolář, as. MUDr. Eva Havrdová, CSc., Marcela Zálišová and others.

The video tapes can be obtained at each MS Center and at Unie Roska, and are free of charge.

2.4. Background of the relatives of people with MS and specific training.

There are no specialized activities in the area of training for relatives of people with MS. They have to find information themselves, on the web, from the specialists or from experiences of other relatives. Currently, there is quite a lot of information about Multiple Sclerosis in the Czech language on the web. These are web sites of both specialized organizations and of people with MS themselves. Internet is a great tool for these people, they can communicate with other people with MS and their relatives, share their feelings and fears, or find some useful information. However, it has to be said that this information is not centralized, nor certified, so there is definitely a lack of some professional training tools for these people.

There should also be a better awareness about Multiple Sclerosis, partly because the affected person and his/her family have no idea about care possibilities in the beginning of the disease, and also general public should be more aware of MS to better understand the MS patients and help them when it is necessary.

To conclude, we can say that despite the first-class physical treatment that MS patients can get in any of the facilities, there is still a lack of care in other than medical sphere. The support in other aspects of life that are affected by patients' disease (social, family, psychological) are not worked with, there are only very few places where family members can get help and support, and very little family education can be obtained as a part of the complex care of a patient. There is some possibility of improvement given the state legislation and proposal for a system of integrated rehabilitation, but that will be a long-term effort that government will have to make. Nevertheless, the society cannot entirely rely on the government initiatives, the society must work within itself and strive to improve the situation of MS patients and their families as part of its existence.

According to this survey, there is a big need to help relatives of people with MS to get to qualified information about the disease and how to care about the patients. Although increasing care is dedicated to patients themselves, no special attention is focused on their family members, despite the fact that they are key persons in the care of the patients.

3. DOCUMENTARY ANALYSIS IN GREECE

3.1. Relatives of people suffering MS. Their role.

MS is affecting not only the diseased person but the whole of family. It is very probable that the members of the family can no longer do what they used to before the diagnosis and they even have to change their roles within the family. The precise advising by experts on the possibilities and the restrictions of the patient is the tool that allows the realistic determination of the role of each member of the family. MS has no constant progress, so every time a reallocation of the roles within the family is necessary. Whatever the situation is, the individuals and the family together have to live in a new reality. MS will intrude the family life; the point is that the individuals must take advantage of the possibilities given in order to continue their life in harmony and efficiently.

Reactions to MS:

I. The spouse.

The initial reaction of the spouse after the diagnosis is confusion and a feeling of compassion for their beloved individual. The loss of health of their companion and the changes that this involves will cause a variety of sentiments and reactions, which are normal reactions of the process of the grief for the pre diagnosis condition of our life. Some of the most common reactions are:

- Anger/ disappointment: why this happened to their relative and not to someone else. They may even be angry, unconsciously, as they took the role of someone who has to take care of someone else, because they will have to undertake the family burdens mainly by themselves or because their economic situation and the quality of their life should change.
- Compunctions: the spouses can then feel compunctions for these thoughts and for the fact that they think only for themselves while the one they love suffers. They may even feel compunctions because they had not realised, before the diagnosis that something was not going well or if they could do something in order to deter this situation and they did not do it.

- Refusal: some people refuse to accept the diagnosis and visit different doctors with their relative until they finally realize that this is a reality. These people usually do not talk to anyone about MS; they react as if it does not exist. They do not make any discussion with the one that suffers on their disease and they believe that they should make to him all kinds of concessions. MS cannot disappear in this way. This lack of communication makes the open expression of sentiments and fears more difficult so there are more compunctions and bitterness from both sides.
- Impasse: the companions of patients often feel that they are found in impasse and that they can do nothing in order to improve their life. In this situation they either give up every attempt to manage their life or try to offer as many as possible to their patient, removing their independence and initiative. It is necessary to find a balance and establish a framework of activities and roles, but this is something that is tough through time.
- Bereavement: The process of bereavement is a natural process through which all the people involved have to go through in order to proceed normally to their life. The open expression of sentiments and fears is necessary for the future. In this way the members of the family come closer and together find the ways to improve their life.

II. The children.

Children whose parents suffer from MS show particular needs and sentimental reactions that can influence their psycho-sentimental condition as well as their ability for adaptation and confrontation with daily requirements.

A lot of parents believe that their condition cannot be noticed by the children or they are very little affected. Children however are very sensitive in noticing all the changes that occur to their family even if they do not talk to them directly about it. It has been proved that children are faced with a variety of sentiments and manifest disorders in their behavior.

The need to maintain the relations with their parents is very important to them. The communication has to be maintained within the family and this can be achieved only if the children are fully aware of the situation and with honesty and simplicity discuss the problem of the parents' illness. In order to inform the children, they will have to take into consideration the age and the peculiarities of the child.

Pre-school aged children give greater emphasis not to lose a parent and have continuous contact and communication with them. School aged children give greater emphasis on knowing what is happening and they have to be prepared for the changes that will occur to their life. It is important to realize that they are not responsible for what is happening. Teenagers express quite often very intense sentimental and behavioral reactions. What they are mainly interested in are the long-run consequences of the disease, the heredity, how long it lasts etc. The most common sentimental expressions of the children on the disease of their parent are the following:

- Fear and concern for the parent.
- Fear and concern for their future.
- Demonstration of psychosomatic symptoms.
- Guilt and undertaking of excessive responsibilities.
- Anger for the loss of previous relation with the parent, when he cannot have the same contact with his child, because of kinetic difficulties.
- Shame because their own parent differs from the others.
- Sadness, disappointment, lamentation.
- Refusal of the situation.

The way in which the parents will react and manage the sentiments of their children is very important in order to maintain the binding within the family. The parents should:

- respect and understand the sentimental and behavioral reactions of their children,
- encourage their children to share their feelings,
- inform them with honesty and in an appropriate manner according to their age about the disease,
- answer on the practical questions that worry the children for the symptoms, the drugs, the hospitalisation and generally taking care of the patient, with honesty and depending on the children's age,

- make sure that the distribution of responsibilities in the house is done in a way that would not put a burden on the child,
- encourage their child to continue having personal interests outside the family,
- if the parents cannot keep up with their children demands for involvement on common activities, they should try to find alternative ways, depending on their stamina, so that they continue to have a contact with them,
- if it is considered necessary, the family should take advice from experts on mental health so that they can maintain the coherence of the family and its connection with other outside-family sources of support.

III. The parents.

The initial diagnosis appears to cause the same shock to the parents as in their child that has MS. It is a usual phenomenon for the parents to feel responsible for the disease. They often wonder if they have done something or did not take care of their child when it was younger with the result that they are suffering from the disease. Many times they accuse their partner or the companion of their child or some other innocent person for the situation. They become over-protective as they think that can pay-off any neglect. The parents of those with MS must understand that they have nothing to do with the condition that their child is facing. Multiple Sclerosis is not a hereditary disease. They must treat their daughter or son as if they were completely healthy. They must offer their help only when it is necessary and allow their child to do as many things as possible. The patient must maintain the right to decide if it needs help and from whom wants to get it.

If the patient wants to talk about his/her problem, the parents must maintain an open communication, listen carefully and not try to impose their own opinion. MS does not need to be the only subject of discussion or the everyday matter.

A positive attitude towards life is very useful in the confrontation of the most difficult situations. People can always see the positive side of things, without denying their seriousness. In the formation of a positive attitude towards life the allocation of time from the side of the parents helps for themselves and their needs.

IV. The brothers.

In every family there can be both positive and negative feelings developed between the brothers that are due to the presence of the illness. The worries and the questions that the healthy brothers have of those that have MS are the following:

- Guilt that they do not have MS while their brother/ sister has.
- Shame for the appearance of their brother/ sister.
- Offering continuous help to the patient, in a point where they neglect their own needs.
- Fear that they may develop MS.

Specially when the brothers of an individual with MS are minors, the above mentioned feelings are accompanied by anger and jealousy as the parents give greater attention to the patient as well as feelings of isolation and differentiation, as their family is different from the rest. In this situation the parents should:

- Allocate quality time to the healthy children.
- Do not put burdens that are beyond those of their age.
- Encourage them to express their feelings.
- Inform them about the condition of the health of their brother/ sister as well as the situations in the family, always depending on their age and their specialties.

V. The social environment.

When a person is informed that has MS, initially may want to talk to his / her family and friends about the problem, but the social stereotypes about disabilities and being different usually drive them to hide their illness and they are thus driven both themselves and their family to a social isolation.

The social environment does not know what MS actually is and differentiates its behavior once they know about the diagnosis. The most distant people of the patients' environment are the

most probable to stay away, as something different scares people. The closest relatives and friends would try to help, but they initially have to be informed about the disease.

Nobody likes to talk only about his/her illness, but the curiosity and the interest is something natural as friends and relatives want simply to help. People with MS must be honest with their friends and tell them that they will ask for their help if they need it. In this way they will maintain their social environment and the possible assistants in << difficult situations >>. There is no need for the patients or their families to feel bad for the assistance from friends or relatives. There will be a time where they will pay-back their assistance in a way that they have not yet imagined. It is necessary for the members of the family to armor themselves against the criticism of their wider social environment, that are not aware of the problem and will hurry to judge the condition or accuse sentiments and roles.

The symptoms of the disease that can cause special problems.

Some symptoms of the disease are not serious and may never get serious. In a few occasions some of the symptoms may influence to a large extent the everyday life not only of the patient with MS but also of the people who take care of them. It is necessary for the relatives that are taking care of the patients, to be addressed to experts that will support them in the adaptation of this new situation. It is basic to have every kind of help.

• **Fatigue.**

Tiredness is one of the symptoms of the disease that is completely misapprehended. The relatives of the people with sclerosis can hardly believe that the patient really cannot go for a walk, cook or watch TV with them. They receive this behavior as refusal, disregard or laziness. In such situations there should be trust and honesty. In this way the person with MS will feel that they understand him and will not feel remorse that is not participating in certain activities. On the other hand the relatives should also be fully informed about the fatigue factor and MS so that they will not feel anger or disappointment for the behavior of the person.

- **Depression and changes of temper.**

Some people with MS develop changes in their mood and behavior with sudden outbursts of anger or sadness that usually do not last for too long. The relatives that take care of them may not be aware of how to react in those changes of temper and quite often they feel disappointed. It is useless to be optimistic all the time and avoid the person until this passes. There is a chance that the person with MS will fall in melancholy or feel useless and undesirable. It is important to feel that the others understand his feelings, but is equally important to get him back to reality. Those that take care of people with MS may suffer from depression. They may feel indisposed and helpless, feel that their help is not appreciated and that have been taken away the right to live as they like. There are times where the situation is out of control. Each member of the family is isolated and disappears from the society. It is then that the family needs to revise its priorities, make changes, choices and compromises. The advice of an expert is necessary that will assist in setting new boundaries and new family roles. Nobody can help someone else, if he / she is not in a good condition.

- **Memory.**

MS can cause knowledge difficulties. Some people with MS may have loss of recent memory or have organizational and speech problems. This can annoy or cause tiredness to a great extent to those that take care of the patient. The management of everyday activities, keeping a diary of the responsibilities and the use of notes can help solve the practical problems of everyday life. The contribution of a work therapist is essential.

- **Incontinence.**

67% of the people with Multiple Sclerosis are facing some degree of incontinence. The sentimental and social repercussions of incontinence may be devastating for someone with MS and it is hard to be accepted by the members of its family. The patients should always be addressed to the Neurologist that supervises them. They may even need to visit a special Urologist, who can, usually with simple tests, determine the cause and the type of incontinence. The experts will determine, depending on the problem the measures that will be taken (use of medicines, use of catheters or physical exercises). The patients' relatives that take care of them must support and encourage him / her to follow the advices of experts, as the distress and the negative attitude can worsen the incontinence.

- **Sexual dysfunction.**

MS does not imply sexual dysfunction, but some people can have organic and/or psychological difficulties that will cause problems in their sexual life. The sexual dysfunctions can be transitory, have fluctuations or of great duration. Tiredness, stress and incontinence contribute to the appearance or the elongation of such problems. The matter of sex is seldom discussed even as the experts mention, it influences 91% of men and 77% of women that suffer MS. Even the experts prefer not to say anything. The sexual problems may lead the person with MS to lack of confidence and a feeling of failure. It is many times hard for their companions to manage their sentiments and the reactions of the patient. A psychologist and/or a special sexologist can help the couple express openly their feelings and their expectations and find ways to maintain their sexual activities (with the use of technological or medical aids). Besides the technological development, even the experts believe that the treatment with the longest-lasting duration is the one that comes from us within because the sentimental and biological sides of sexual activity are interrelated. "The picture that we have for our sexuality plays an important role" is stressed by Nancy Holland. "We can reach sexual satisfaction in various ways; the companions should however learn to feel comfortably with their body, collaborate in order to overcome the personal and social prejudices that are related with sex". "The technology and medicines certainly help a lot, but definitely no technology can correct immediately a relation that has problems and declines", says Michael Barrett, Ph. D., member of the Administrative Council of the Centre Sex Information and Education Council and author of the book *Sexuality and Multiple Sclerosis*. In other words, the most important factor to overcome the sexual difficulties is the quality of relation with the companion and the will for experimentation with new ideas and ways.

- **Buoyancy.**

MS can cause alternations of crises or progressive permanent increase of symptoms. During these crises new symptoms may appear or older symptoms that had withdrawn may reappear. This buoyancy can last from a few days or even months, and can be light or of very heavy condition. This can start for no particular reason but may appear after a contagious illness, by a wound or from psychological tension. When the symptoms disappear completely or partly, the patient's condition can improve and this can remain for weeks, months or even years. It is impossible to predict how the disease will develop, as these symptoms differ between patients.

This is something that the patients and their families must accept without worrying about the future. The periods where the symptoms increase are definitely unpleasant, but for many people the symptoms disappear and they enjoy a period of ease. This instability of the disease can wear out the patients and the people that take care of them, result in losing their self-confidence and the feeling of self-control of their life and feel trapped. The support by the social environment plays an important role in order for the periods of crises to be faced. The distant relatives and friends will need some education in this matter.

- **Kinetic disorders.**

MS can affect any area of the central nervous system. Spastic paralysis is one of the main indications of the disease and affects 90%- 95% of the patients. It is serious in later stages and causes walking difficulties and disorders in the arms and on serving themselves. 70% of patients have weaknesses which usually appear earlier in the legs and is more serious than the ones in the arms.

- **Disarray - tremble - Dysmetria.**

These symptoms appear not only in the arms and legs but also the torso. They cause difficulties on serving themselves in their everyday activities. The tremble makes it hard for the patient to eat alone and drink coffee, get dressed or write. Dealing with this is very difficult. These problems complicate the everyday life of the patients and of those that take care of them. Their confrontation requires the use of medicines, physiotherapy and generally the contribution of special doctors. The relatives of individuals with MS that take care of them need special education as the patient has to do certain exercises in the house and requires help for his daily needs. The search for assistance from special nursing personnel and the benefit of advices and information from the experts are essential elements for the maintenance of harmony within the family.

3.2. Support and help the relatives receive for the care of the person with MS.

- **General Practitioner.**

The patients and the individuals that take care of them should consult a general practitioner or their family doctor if they worry for any matter of health. It is important that the couple must visit together the doctor, so that there is discussion about the subjects that concern both of them and will become comprehensible that the disease is a subject of the family and not individual.

- **Neurologist.**

Neurologists are special doctors that make the diagnosis and give the therapeutic treatment for the diseases of the nervous system. It is important that the neurologist is an individual that the patients and their relatives can trust and feel free to discuss openly with him / her all the symptoms of MS that bothers them and influences their everyday life.

- **Physiotherapist.**

The physiotherapists help in problems of mobility, balance and movement. The relatives will have to assist the patients in order to do certain exercises at home. The physiotherapist becomes during the course of the disease a good adviser for practical questions.

- **Occupational therapist.**

Occupational therapists can give practical advice for the organisation of the daily life and the configuration of space, in order to achieve the highest level of autonomy for the patient. Simple advice for the arrangement of objects at home, for the use of certain mechanical aids or for the keeping of a diary of activities help the patient to feel autonomous, improve his / her self-respect, while simultaneously relieving their relatives that take care of them, as they organize their everyday life and set boundaries and responsibilities.

- **Speech therapist.**

Speech therapists appreciate and heal people that have difficulties with speech, swallowing or communication.

- **Social worker.**

The role of the social worker is to realize along with the patients and their relatives their needs. They determine the kind of help that the family needs and inform those interested in the various social benefits and the institutions that can be addressed for help.

- **Expert for the incontinence.**

A lot of medical centres in our days have special doctors and nurses for the incontinence. They determine the dimension of the patient's problem and indicate the suitable treatment and way of confrontation. It is advised that the relatives of individuals with MS that take care of them, encourage the patient to visit those experts, go together, so that it becomes comprehensible that the incontinence is one more symptom of the disease and can be treated.

- **Psychologist.**

The psychologist is the individual that will help the patient and the individuals of his / her direct environment to accept the new situation and face the life by taking advantage of their new possibilities. To maintain mental health, personal expression and communication and setting boundaries and roles within the family are necessary elements for the confrontation of the new situation.

3.3. Entities offering the relatives support for the care tasks.

Legislation – benefits.

• Public Insurance funds.

Social Insurance Institute (I.K.A):

- Pharmaceutical care: those that suffer from MS and are insured with I.K.A do not pay anything for the medication that they receive.
- Additional care: anything required for additional care has to go through the authorization of the relevant to the disease doctor of IKA and be approved by the controlling doctor. For some of the things required, the beneficiary has to pay for the 25% of the price. They are exempted from payments for the supply of wheel chairs, artificial limbs and orthopaedic aids those suffering from paraplegia or quadriplegic. Moreover those suffering from MS do not bear the expenses of sanitary material that they need (catheters, urine collectors, other materials).
- Spa therapy: I.K.A subsidises those directly insured and pensioners, which for therapeutic reasons are in need of spa therapy.
- Program of therapeutic tourism: I.K.A in collaboration with the Greek Tourism Organism implements programs of therapeutic tourism,- for the economically worse groups and for the insured that will not take the benefit of spa therapy – targeted to 15.000 people that have a need to receive spa therapy for 16 days in 5 spa cities in Greece.
- Hospitalisation abroad: I.K.A is covering all the expenses in the case where the disease cannot be diagnosed and treated in Greece. They cover the cost of the tickets and a percentage for the living and food expenses of the patients and his escort.
- Para/ quadriplegic allowance: this allowance is given to those suffering from paraplegia or quadriplegia in a percentage of 67% or above. Beneficiaries are the directly insured and also the members of their family.
- Pensions for the disabled: Pension for disability is provided to those that are not able to work, once they have been examined by a special board.

Paraplegic allowed and disability pensions are provided by all the insurance funds in Greece, once they have been improved by the special boards.

• Other public benefits:

- Paid leave from work: According to the law 1648/ 86, disabled employees are allowed an extra 6 days of paid leave every year. Also, according to the law 2527/ 97, all the employees of the public sector that have children with 67% disability, certified from the health boards, are eligible to reduced working-hours of one hour every day without proportional reduction to their wages. This reduction is extended for paraplegic/quadriplegic employees, without any cuts on their wages. These benefits do not apply in the private sector.
- Outside- institution allowance: According to the law 1140/ 81 and its amendment (law 2042/ 92), a special allowance was established for those suffering from quadriplegia/paraplegia. This allowance is not referring to a specific illness, but covers all the citizens (as well as those with MS) that for any reason suffer from paraplegia or quadriplegia. In order for someone to receive this allowance, he will have to be insured in any Social Insurance fund and have a disability of more than 67% by paraplegia or quadriplegia. If the person is not personally insured, but is a protected member of someone who is insured, can then receive the allowance. This allowance is given even if the beneficiary starts working.
- Transportation cards for the disabled: People with special needs that have pathological or anatomic percentage of disability of at least 76% are provided with the right to use transport tickets with 50% discount in all trains routes and public buses within their city. These people get a card for unlimited routes that is valid for one year.
- Special Committee for People with Disabilities: In the Ministry of Internal Public Administration and Decentralisation a special committee for people with disabilities is in operation, in which participate qualified people from other ministries as well as representatives of institutions for the individuals with special needs. The main role of the Committee is the induction and the follow-up of concretisation of measures for the facilitation of access and the improvement of services of people with disabilities in the public sector (removal of architectural obstacles in their access, legislative regulation for the reduction of the schedule of work for the parents of individuals with disabilities of 67% or more and for the spouses of individuals with disability 100%, awareness of the public in matters that concern the special needs etc.).

➤ **The Program « Help at Home »**

The program « Help at Home » is a social protection program with the aim to provide organised and systematic care for the elderly, people with disabilities and provisionally indisposed individuals.

It provides:

- advisory and psycho-sentimental support (for individuals and families),
- nursing care,
- care of household,
- keeping company,
- shopping / servicing,
- help in the individual hygiene,
- other services that are considered necessary.

It ensures:

- the decent and autonomous living conditions,
- the eve of individual in the natural family and social environment,
- improve their quality of life.

It is a program run by the Ministry of Health and Care that is materialised with the responsibility of Local Governments. The services are provided free of charge to the houses of citizens that need them. Today this program is applied to more than 80% of Municipalities of Greece and is partly-financed by the 3rd Community Support Framework.

➤ **Citizen Service Centers.**

“Citizen Service Centers” is a one stop shop service aimed at the improvement of the efficiency of public administration and the total qualitative improvement of service provided to citizens.

The creation of Citizen Service Centers aims to facilitate the relations of citizens with the public sector, simplify the processes, reduce bureaucracy and lay the foundations of electronic administration.

People with MS and their relatives can be addressed at those centres in order to receive any information that concerns their relations with the public sector as well as information that concerns their legal rights and the institutions in which they can be addressed to for help. The Citizen Service Centers provide also information via telephone and operate extra hours in order to facilitate workers.

The responsibility for the operation of those centres is on the Ministry of the Interior, Public Administration & Decentralization. This service is partly-financed by the 3rd Community Support Framework.

➤ **Actions of the Greek Red Cross.**

Program «in house hospitalization»: this voluntary service is in operation since 1990 and is targeted to patients, whatever their economic situation is, with the condition that they live within their family environment and they are in the region this service is covering (this program covers the region of Athens). A specialised scientific team that consists of nurses, doctors and physiotherapists offer its services and takes care for the re-establishment and rehabilitation of patients in the community, with their support and of their families. There are also educational seminars held for the relatives of patients that take care of them, on subjects of patient caring in the house.

Social Welfare Sector: operates since 1965 and supports programs for the confrontation of modern social needs, the protection and help of corruptible demographic groups. In collaboration with other social institutions, the volunteers of Social Welfare (among others) participate in programs for the physical and mental health, for the protection of individuals with disabilities and their families as well as programs of friendly visits.

➤ **The Greek Multiple Sclerosis Society.**

The Greek Multiple Sclerosis Society is a non-profit, non-governmental association based in Thessalonica, with over 3.500 members in Greece. It is operating in Greece for 12 years aiming at:

- the support of individuals with MS, in order to achieve their autonomy, as soon as possible and with minimum effort;
- the improvement of their everyday life aiming at their attendance in daily productive events;
- their re-integration, through their professional involvement in the society;
- the sensitization of the society over the problems that this disease creates;
- the contribution so much in the right use of the existing treatments, as well as in the research for the discovery of a complete treatment;
- the reliable information of those interested (patients, relatives, therapists etc.) on issues relative to the disease.

The Greek MS Society has offices in Athens, Thessalonica, Alexandroupoli, Larissa, Kavala, Heraklion, Syro, Rhodes, Corfu and Patras, operating by people with MS - volunteers. It is a member of the Pan European organisation for MS (EMSP) and regular member, from the 43 member countries of the International Federation of Societies for MD (MSIF), based in London.

The Greek Society for MS carries out the following activities:

- Participates at the major European and world congresses and organises Pan-Hellenic congresses, meetings and lectures in the whole of Greece for the up-to-date information with regard to the disease.
- Collaborates with doctors in hospitals (Neurologists, orthopaedists, oculists, urologists) as well as psychologists, physiotherapists and social workers.
- Distributes information booklets relative to the disease and publishes a quarterly newspaper that is dispatched to members, neurologists and in Greeks abroad.
- Organises meetings for acquaintance and exchange of opinions between the patients and their families, as well as recreational events.

- Provides telephone information and psychological support for patients and their families.
- Has voluntary teams of self-assistance for house visits to those whose condition is worse.
- Its members participate in teams of various activities (Physiotherapy, exercises in swimming-pool, aerobic gymnastics, psychological support etc), offered voluntarily by specialists.
- Demands from the state and the society active support to those suffering and their families.
- Promotes the scientific research and modern scientific information with regard to the disease.

➤ **Centres of Full recovery and Rehabilitation.**

The key for the limitation of the multiple negative effects and the complications of MS is exclusively the composed and effective treatment of rehabilitation. This means that the patients and their relatives are provided, those that have taken over their caring, with complete therapeutic programs which are formed on the base of the appreciated needs and the forecasted possibilities for rehabilitation of the patient.

The Rehabilitation treatment for patients with MS is offered only in special Centres of Rehabilitation and by special Rehabilitation Teams. These centres are self-existent and independent units, in which the infrastructure, the equipment and the staff are determined by the Legal Framework (N. 2072/ 1992- ΦΕΚ 125), is imposed by the European Union and in effect in Greece country since 1992.

The Rehabilitation Team of Full recovery and Rehabilitation Centres consists of special scientists of two basic Therapeutic sectors:

- *Sector of Natural Medical Treatments:* physiatrists, physiotherapists, biofeedback specialists, gymnasts, work therapists, endocrinologists, dieticians.

- *Sector of Psychosocial Services*: neuropsychologists, speech therapists, psychopathologists, psychologists, social workers, advisers of professional orientation and training.

- Centre of Full recovery and Rehabilitation «Anaplasia»: in this model Centre that functions in Athens, completely individualised programs for the rehabilitation of patients with MS are applied depending on the symptoms of the patient and the way the disease progresses. The innovations applied in this centre are the following:

√ *Introduction of Daily hospitalisation*. The patient, at the end of the therapeutic session, returns to his / her house and work where applies whatever is taught at the center. In this way the patient is not isolated by the social environment, while the family is participating in the process of Full recovery. Moreover, by working, the patient can offer financial support to the family and assist financially the relatives that take care of him / her.

√ Offer total care. Therapists of different specialties are simultaneously present at the therapeutic sessions, ensuring thus the total approach of the problem and the therapeutic confrontation. In the same way, the joint collaboration with the patient and his / her environment is achieved, that actively participate at the treatment.

√ Offer consulting - psychotherapeutic services. The center psycho-health specialists evaluate and offer therapeutic treatment for the mental problems of patients with MS, such as sentimental disorders (stress) and difficulties of adaptation in the conditions of the disease and treatment of Rehabilitation. There is also support and training of the patient's relatives provided, aimed at their best possible adaptation at the new conditions and their participation at the treatment.

√ *Guidance and practical exercise in the field of Self- Servicing*. This department consists of a specifically shaped apartment (representation of places of residence with complete equipment). By offering practical exercise the patient with MS gains greater autonomy in his activities of his everyday life (feeding, clothing, individual hygiene) requiring thus less assistance from his relatives.

√ *Guidance of the patients and the relatives in making changes and improvements at their home*, in order to maximize the autonomy and independence.

- Full recovery and Rehabilitation Centre «Anelixi»: Anelixi is a day care center of Rehabilitation – Full recovery, situated in Athens and focuses besides others, to patients suffering from Multiple Sclerosis. The specific center has completely trained personnel consisting of a Natural medicine and Rehabilitation doctor, Physiotherapist, Work therapist, Speech therapist, Clinical psychologist and a Rehabilitation Social Worker. The innovations applied by this centre are:

√ *Consulting services*. Besides the psychological and consulting support of the patient with MS and of his family, the center has a service which is called «Consulting for Social benefits ». Through this service the patients and their relatives can be informed about their legal rights as well as the authorities to which they can be addressed to for help.

√ *Hospitalisation at home*. The center is offering the possibility for the Rehabilitation team to go to the patient's home. The particular needs of each family are determined and various treatments are provided or medical services, if the patient is unable to move to the centre.

√ *Application of educational programs*. The center, taking into consideration the educational lacks and needs of the patients and the relatives that take care of them, organises educational programs in order for them to learn about the problems created by MS and the possibilities of self-caring that the patient has, depending on the condition of his health.

“Anelixi” also organizes informative, popularized lectures and video presentations in order to make accessible the scientific knowledge and information to the patients and the relatives that take care of them. (www.anelixi.gr).

The statute of operation of the Full Recovery and Rehabilitation day care centers is something relatively new in Greece. The centres that were described above as models have been created by private initiative and have contracts with most – not say all- of the public security services in Greece. In the last years other similar centres were created all over the country either by private initiative or through non- profit organizations or associations. (www.disability.gr)

3.4. Background of the relatives of people with MS and specific training.

Most of the individual's relatives that suffer from MS have no educational background on what the disease really is and what they can do in order to help and take care of them.

When the disease is diagnosed, most people are shocked and feel confused in relation to the new for them situation of their life. The knowledge of relatives, but also of patients concerning the MS is limited on what they have heard from the mass media or have read occasionally in the press or still in vague information from somebody that suffers from MS. Most of the interested people do not know exactly what to ask their doctor in order to get to know and understand the disease, so as to learn how to live with it. The variety of symptoms and the unpredictability of the disease make it difficult for the relatives of patients with MS to respond to the everyday care that they have undertaken.

As we can see at a first glance from the empirical analysis of the project, most of the people that have undertaken the care of individuals with MS, have acquired the required knowledge empirically, through the daily caring.

There is no organized educational program for the relatives of individuals with MS in Greece, with the exception of certain private initiatives (see Full recovery - Rehabilitation Centres).

There are however certain institutions that have taken the initiative to cover the educational needs of patients, but also the relatives that take care of them. These institutions are:

The Greek MS Society.

The Greek MS society with its 10 local offices all over Greece, tries to cover, as far it is possible the educational and information needs of people with MS and of their families. The society's offices offer information about the disease, its complications, the approved medical treatments and other welfare subjects. The society's actions in this direction are:

- *Publication of newspaper «Information on ms».* The newspaper of the Greek MS society is delivered to its members all over Greece by Athens's office and to 2500 health professionals and

friends of the society. It is also delivered to Cyprus and to Australia's MS society for the expatriates that suffer from MS. The aim of the specific action is the regular contact of the society with its members.

The subjects of each issue are chosen from the recording of questions and queries that people who are members of the society make over the phone. The members are encouraged to send letters for publication and make suggestions on subjects on which they would like to have further information.

For the patients with MS and their relatives who live outside the main cities, this newspaper is the only source of information that they have.

- *Organisation of Meetings, Speeches and congresses.* The Greek MS society is organizing in regular time intervals meetings and speeches in various regions of Greece, while once every year takes place a Pan-Hellenic Congress on the sclerosis.

Through these activities patients with sclerosis and their relatives have the ability of being informed from scientists of many specialities with regards to the last developments that concern the disease. They can also ask questions and take answers from the most trained and experienced individuals.

- *Publication of booklets – informative leaflets.* In order to offer the same quality of information to all and mainly for recently- diagnosed patients and their families, the Greek society publishes and distributes free informative leaflets. These leaflets aim to help the patients with sclerosis and their relatives that take care of them to the various dimensions of the disease. There are publications relative to where they can ask for assistance, how to inform their children and their social environment about the disease, how to manage their sentiments and how to organize their everyday life in order for their family to remain united and operational.

The society is also publicizing booklets with practical subjects on the patients' lives. There is also a booklet in circulation with exercises that patients can do at home in order to improve their movements. There is another booklet for the disorders of the urinary system and one more for the sexual disorders that sclerosis causes.

- *Telephone consulting services.* Many patients and those that take care of them haven't got the ability, due to their increased responsibilities and/ or of the distance to attend the seminars, the meetings or the offices of the Greek society and get informed about the matters that worry them. For these reasons the personnel of local offices of the society provide telephone information on the last developments relative to the disease. The personnel of the offices are always informed and can answer in any of the members' queries.

There is always open communication with its members over the phone. There are even telephone numbers for outside working hours communication. This support over the phone has helped many people that were facing their condition from the wrong point of view, due to their ignorance.

- *Face to Face assistance.* The offices of the Greek MS society are open to all patients with MS and their relatives in order to get information on practical subjects or for sentimental support. All the local offices hold weekly meetings with their members, in which those that face similar problems can share their experiences and support each other.

- *Web Site.* The Greek MS society has created a web page, which offers every kind of information relative to sclerosis to everyone interested, that for certain reasons cannot have a face to face communication. (www.greekmssociety.gr).

Disabled Hellas.

Disabled Hellas is a non-profit organization, that has the aim of providing every kind of information to people with disabilities in Greece in order to improve their life.

It is a web site (www.disabled.gr), totally accessible to people with disabilities and offers a great amount of information and services.

Disabled Hellas created the first on line library, which contains 383 articles and books in Greek and 835 articles and books in English.

In Disabled Hellas people with MS and their relatives that take care of them can find:

- Magazine «Disability now» (www.disabled.gr/anapiria.htm) which has 950 subscribers with MS.
- «Lavda» (www.disabled.gr/lavda/index.html), which is the first centre for the Independent existence and offers information with regard to tutors and assistants of the individuals with disabilities and their relatives.
- A catalog of the Greek organization (www.disabled.gr/gr-dis01.htm) that are on line.
- List of Greek enterprises that sell products for the individuals with disabilities.
- List of electronic mail (www.disabled.gr/newsletter.html), in which people come together and discuss about the similar problems they face, express their queries and questions which are answered by volunteer scientists of various specialties.

Moreover, in www.disabled.gr, there are web pages of people that are involved in subjects related to MS, like:

1. Maria Zei (www.disabled.gr/mary) with translations and documents about MS.
2. Efi Katsoyraki (neurologist) (www.disabled.gr/koutsouraki) with articles on MS and others(www.care.gr)

Despite the efforts for support, information and educational training for the relatives of people with MS that have taken over their care, there is no organized educational program in Greece in this direction. This is where the European project QUALIFIED CARE - that aims at the detection of the educational needs of care givers of individuals with MS and the creation of educational material to cover their needs, is pioneering and is expected to cover a big gap of the Greek reality.

4. DOCUMENTARY ANALYSIS IN ITALY

4.1. Relatives of people suffering MS. Their role.

- Social and economical situation analysis related to persons with MS.

In Italy there are 1.800 new diagnosed cases every year, 50000 cases with an annual social cost of over 2.500 million. In the world 3 million of people are affected, 400000 in Europe. It concerns above all women (the relationship is of 2:1 in comparison to the men) and the symptoms manifest him in the majority of the cases between the 20 and the 30 years. MS is an illness from the strong social impact whose repercussions on the private sphere of whom are dramatic. But in the last years a lot of things have changed: to start from the diagnosis that it can be done since the first symptoms, and from the therapies, able to prevent at least a part of the new attacks and to slow down the progression of the neurological damage that can bring to the disability in the time.

A clear and punctual communication during the diagnosis, the specialised medical support, the expansion of the services offered by the centres of reference, the multidisciplinary approach to the disease, the comparison with the other patients. Close to the person with multiple sclerosis they have also involved relatives and friends involved from practical implications, sensitive person and affectivity.

In Italy, the annual middle social cost for a person with MS is of around 25 thousand €. But the figures change in substantial way with to advance some disability: he passes from the around 15 thousand € annual for a mild disability, to 34 thousand € for a person walking with support. And a joined study of the FISM (Italian Federation SM) and some estimates of the Italian Institute of Health has quantified in 43 thousand € the annual social cost for a person with MS forced completely not to the use of the baby carriage and in 58 thousand € that for a self-sufficient patient.

But besides the direct costs which you hospitalise, specialist visits and examinations, those indirect exist, also tied up to the loss of productivity of the sick person and of whom assists her/him, over that from the load for the informal assistance. According to a study conducted by the AISM-MUSIC (Multiple Sclerosis Italian Costs), altogether every year 1.400.000 days of job

are lost from the 50.000 patients affected from the illness in Italy and from the people that they assist. Each of disease need in one year of almost 1.300 hours of informal assistance, that is not professional, from relatives and friends. The hours of assistance reach 2.500 in case of increased even some disability and double for the most self-sufficient people.

- Health condition and therapies for persons with MS.

It is not rare to see patients with more advanced forms of the disease who have lost all family support, are separated from their spouses, constantly require psychiatric and nursing assistance, and are unable to walk. These patients create a challenge for the physician who is not trained in handling these demanding (administrative or ancillary) aspects of medical care. In addition, the physician should not underestimate the impact of fatigue symptoms on the patient's daily activities.

Fatigue.

Fatigue is described as an overwhelming feeling of lassitude or lack of physical or mental energy that interferes with activities. An estimated 50-60% of persons with MS describe it as one of their most bothersome symptoms, and it is a major reason for unemployment among MS patients. Rule out comorbid medical conditions, such as infections, anemia, or thyroid disease, before attributing fatigue to MS. Medications used in MS management often can contribute to fatigue. These drugs include analgesics, anticonvulsants, antidepressants, muscle relaxants, sedatives, and immune-modulating medications.

Amantadine is perhaps the first-line drug used to treat fatigue. Approximately 40% of people experience some relief of fatigue. Other drugs that have been tried in fatigue management include methylphenidate and fluoxetine. A disadvantage of methylphenidate use is that it is a controlled substance. For those with concurrent depression, fluoxetine may be tried to manage both problems.

Nonpharmacologic treatment of fatigue involves energy conservation, work simplification, scheduled rest periods, and use of a cooling vest.

Spasticity

Spasticity in MS is characterized by increased muscle tone and resistance to movement, which occurs most frequently in muscles that function to maintain upright posture. As a result of increased stiffness, much more energy is expended to perform ADL, which, in turn, contributes to fatigue. With decrease in spasticity, the patient experiences more freedom of movement with less energy expenditure. Treat spasticity when it interferes with function, mobility, positioning, hygiene, or activities of daily living. Spasticity can be managed through both nonpharmacologic and pharmacologic means. Complications of inadequately controlled spasticity include pain, contractures, and pressure sores. The first step in spasticity management is establishing a stretching program in which each joint is moved slowly to a position where the spastic muscles are stretched. Each position is held for at least a minute to allow the muscle to relax slowly. Stretching exercises may be performed in a cool (85°F) pool with the benefit of the water providing buoyancy and serving to cool the body. Mechanical aids, such as ankle-foot orthoses (AFOs), also can be useful in spasticity management.

Pharmacologic treatment of spasticity includes baclofen (Lioresal) as a first-line drug. Baclofen is effective in most people, is inexpensive, and is titrated easily from 10-140 mg/d in divided doses. Patients may complain of fatigue or weakness as a side effect. Second-line agents include benzodiazepines, such as diazepam and clonazepam. While these compounds can be useful adjunct medications, they can be sedating and habit-forming. For patients who also experience sleep disorders, the provider may take advantage of the sedating side effects of the benzodiazepines to manage both the spasticity and sleep problem with a single medication. Newer medications to manage spasticity include gabapentin (Neurontin) and tizanidine (Zanaflex). Gabapentin is an anticonvulsant drug, which is particularly useful in patients who experience both spasticity and neuropathic pain.

Tizanidine has effects similar to baclofen, producing less weakness but more sedation. Additional treatments for severe spasticity management include intramuscular botulinum toxin, phenol nerve blocks, and intrathecal baclofen pump placement. These treatments are more invasive and usually are required in the most difficult cases.

Bladder problems

Urinary symptoms are common in MS, with most patients experiencing problems at some point in their disease. Bladder problems are a source of significant morbidity, affecting the person's family, social, and work responsibilities. Bladder dysfunction can be classified as failure to store, failure to empty, or combined dysfunction. Patients with failure to store difficulties have a small spastic bladder with hypercontractility of the detrusor muscle. Symptoms experienced may include urgency, frequency, incontinence, and nocturia. Interventions include scheduled voiding, limiting fluid intake in the evening, using anticholinergic medications (eg, oxybutynin), and eliminating diuretics. Failure to empty is characterized by a large flaccid bladder and an inability of the urinary sphincter to relax. Symptoms include urgency, frequency, hesitancy, nocturia, incontinence, incomplete emptying, and frequent urinary tract infections. Interventions include intermittent catheterization or use of alpha-blockers. Combined dysfunction is due to incoordination of the detrusor and sphincter (dyssynergia). Symptoms in combined dysfunction are similar to those of failure to empty. Interventions may include anticholinergic medications or intermittent catheterization.

Bladder problems usually can be managed appropriately after a careful history, physical examination, and urinalysis. If initial attempts at symptom management are not effective, more studies, such as renal ultrasound, voiding cystourethrogram, renal scan, or urodynamic studies, may be indicated.

Bowel problems

Constipation is the most frequent complaint concerning the bowels in patients with MS and is characterised as the infrequent or difficult passage of stools. Constipation may be the result of a neurogenic bowel or of immobility, which leads to slowed bowel activity. Finally, patients who have limited their fluid intake in an attempt to manage bladder symptoms or those with limited access to fluids due to immobility tend to have dry hard stools. A bowel program is most effective if done at least every other day and preferably after a meal, which takes advantage of the body's gastrocolic reflex. Sitting in an upright position, rather than lying in bed, permits gravity to assist in

evacuation. The patient should be involved in an exercise program, consisting of walking or simply performing chair exercises. Diarrhoea, if it occurs, typically is not related to MS. Drugs that slow the muscles of the bowel, management include proper positioning, abdominal massage, and digital stimulation. Abdominal massage performed in the direction of bowel peristalsis, from ascending toward the descending colon, can be useful. Finally, digital stimulation, in which a lubricated finger is inserted gently into the rectum and moved side to side along the wall of the rectum, can stimulate a bowel movement.

Pharmacologic management of constipation includes stool softeners, bulk formers, or laxatives. Stool softeners, such as docusate sodium, work by decreasing surface tension, allowing water to enter the stool. Laxatives act as an irritant to the bowel, increasing peristalsis; they generally work within 8-12 hours. For patients with a neurogenic bowel or with poor abdominal muscle tone, rectal suppositories may be part of an effective bowel program that can help prevent incontinent episodes. Suppositories provide rectal stimulation and lubricate the stool.

Cognitive dysfunction

Estimates of prevalence of cognitive dysfunction in MS range from 40-70%. No correlation exists with the degree of physical disability, and cognitive dysfunction may occur early in the course of disease. This complication of MS can be a significant problem affecting family and social relationships, as well as employment. Areas of cognition affected include comprehension and use of speech, attention, memory, visual perception, planning, problem-solving, and abstract reasoning. Treatment approaches for cognitive dysfunction include cognitive retraining and use of compensatory strategies. Cognitive retraining involves use of repetitive drills and mentally stimulating exercises designed to strengthen those areas of cognition that are weak. Compensatory strategies emphasize coping methods or organizational skills to help the individual use his strengths to compensate for areas of relative weakness, including such strategies as maintaining a consistent routine, making lists, keeping a daily planner, and organizing the home or work environment. In providing education on MS management to patients with cognitive impairment, it is important to involve family or caregivers in training, provide step-by-step instructions, and present information in both a visual and verbal format. New topics should be presented at times when fatigue is less likely to be an issue.

Pain

Pain is a common occurrence in MS, with 30-50% of patients experiencing pain at some time in the course of their illness. Pain typically is not associated with a less favourable prognosis, nor does it necessarily impair function; however, since it can have significant impact on quality of life (QOL), it needs to be treated appropriately. Pain in MS can be classified as primary or secondary. Primary pain is related to the demyelinating process itself. This neuropathy pain is characterised often as having a burning, gnawing, or shooting quality. Non-pharmacological techniques, such as use of imagery or distraction, can be helpful. Transcutaneous electrical nerve stimulation (TENS) is useful in some patients. Pharmacological approaches include prescription of tricyclic antidepressants as first-line drugs.

Secondary pain in MS is primarily musculoskeletal in nature, possibly due to poor posture, poor balance, or abnormal use of muscles or joints as a result of spasticity. Non-pharmacological treatment for secondary pain includes moist moderate heat, massage, physical therapy, and exercise (eg, stretching). Pharmacological agents include non-steroidal anti-inflammatory drugs (NSAIDs) or other analgesics. Use of narcotics seldom is indicated.

Heat intolerance

Persons with MS often experience an increase in symptoms of fatigue or weakness when exposed to high temperatures, due to weather, exercise, or fever. To manage heat intolerance, outside activities should be timed for early morning or evening hours to avoid the heat of the day. Activities should be spread throughout the course of the day to avoid overheating. Air conditioning in homes and cars, cooling vests, light coloured clothes, and wide-brimmed hats can be used to manage heat intolerance. Exposure to saunas, hot tubs, or even hot showers or baths should be avoided.

- Rehabilitation Program in Italy.

Mainly, it provides to apply the treatment discussed below:

Physical Therapy: Physical therapists provide assessment of gross motor skills (eg, ambulating) and assessment and training in appropriate assistive devices to improve mobility. They evaluate and train the patient in appropriate exercise programs to decrease spasticity, maintain ROM (Range of Motion), and strengthen muscles. They also provide invaluable input into the prescription of appropriate seating systems for the non ambulatory patient.

Occupational Therapy: Occupational therapists are skilled in assessing the patient's functional abilities in completing ADL, assessing fine motor skills, and evaluating for adaptive equipment and assistive technology needs.

Speech Therapy: Speech therapists assess the patient's speech, language, and swallowing and may work with the patient on compensatory techniques to manage cognitive problems. In some cases the utilisation of specific aids (also technological or PC based) is considered with the action of counselling centres.

Medical Issues/Complications: A number of medical complications affect patients with MS. Fatigue is one of the most commonly reported symptoms, experienced in up to 90% of patients with MS.

4.2. Support and help the relatives receive for the care of the person with MS.

Persons affected by MS require different levels of assistance, as it is related to the psycho-physical conditions of the person. The illness produces different degrees of disability during the person life. Leaving out medical digression about, we can point out the major situation during the progression of the pathology:

1) during the pousse events and immediately afterwards the person need an intensive care that is normally assured in hospital or rehabilitation centre;

2) during the normal life a maintaining therapy could offer a sustain to the ADL and in general abilities of the person, during these periods (that represents the most of the person life) a public or private assistance could help the person and his/her family.

It will be very important to analyse the needs and the support offered during the periods of normal life of the patient at home. The intensive care is normally performed in well-equipped clinical centres following well-established international protocols. The use of pharmacology treatment (Interferon..) as well as the inclusion in the clinical treatment of medical treatments (TENS..) or the rehabilitation based on physiotherapy and occupational therapy are widely performed in Italy as well as most of the EU countries.

The normal life of the People with MS is represented by the life at home, possibly coming back to her/his occupation and helping herself/himself in performing daily activities. This situation and the problems related to represent the basic requirement to the family care givers. Their load (work-load) may vary on the basis of the clinical situation of the person and the presence or absence of entities helping in sustaining therapy.

First of all we must consider that the family situation normally determines the quality of relations and part of the so-called quality of life for the person himself. This observation brings to consider the effect of this research as directed to mitigate the family stress and to help to reach a better environment for the life of People with MS.

The main needs of the person with MS and the family are the following:

- a) The psychological support: the chance to receive this help is important twofold, on one side helping persons to understand better the relationship with the relative affected by MS and the evolution caused by the pathology, on the other side the family care givers themselves needs to be supported (not only with awareness) in their continuous help and assistance, in their relationships with operators, in the organisation of their life.
- b) The practical support for autonomy development: intended as the way to put in place strategies to maintain autonomy in daily living task (including occupation or employment), they are mainly related to the perceived quality of life of the person which is influencing the quality of life and the wellness of the relatives; in particular we are referring to the occupational therapy tasks, those related mainly to the upper limb functions, to the utilisation, adaptation and personalisation of tools and aids for the ADL; in this sense we have to mention the technological aids, as they could be adapted and operated by persons with a severe disability in order to perform simple tasks (controlling a TV) or to enhance their communication (as VOCA or iconic communicator). Differently from the adoption of a wheelchair, the pathway for the adoption of this type of aids is not well defined yet: the evaluation, the prescription (intended as the economic support for their purchase), the adaptation and the effective evaluation are matter of discussion in Italy. The chance for the relatives to be involved in this type of choices and in the management of the aids is felt as success factor (as they will be involved in aid utilisation/training and maintenance);
- c) The support for the sustaining exercises: it means the need to have a continuous finalised activity as part of the normal ADL; these exercises are aimed against the fatigue, tremor and mostly to enhance compensatory behaviour of the arms/legs in order to maintain the level of autonomy; in some cases exercises could be useful to verify the effect of pharmacological treatment on the person (i.e. blacofen); normally some tools derived from occupational therapy are used (soft balls, hand exercisers, ribbon elastic bands...).
- d) The development of strategies for increasing autonomy: it means a list of exercises/activities which induce the change in the normal way to perform ADL as the pathology produces an

increased impairment; in this case the utilisation of specific aids is useful to compensate the disability: they could very simple (as modified forks, knives, spoons for self feeding activity) and/or more complex like adapted remote units to manage TV, stereo and Home Automation appliances; seldom the development of strategies means (under a direct responsibility of the caring unit) the modification of the living environment, some cases were financed and managed by relatives themselves.

4.3. Entities offering the relatives support for the care tasks.

The situation in Italy can be analysed as a mutating system that is slowly evolving to a network centred system. It means that starting from the assumption that an effective intervention in each social and sanitary issue will be achieved only by the real collaboration of different expertise represented by different institutions of the welfare state. This approach is widely diffused in Italy: an example is constituted by the school integration of the disabled pupils. In this case, health and sanitary evaluations are supporting the intervention of the specialised tutors/teachers operating in the schools, where they are collaborating with the normal (curricular) teachers and other social actors (like the social workers working at pupil home) and the family itself. This way is replicated in several context and it represents the paradigm of an intervention that is 'network centred' instead of 'person centred'. The consequences of this approach are related mainly to the involvement of the social and sanitary bodies, to the complexity of the process and the ideal design of a larger support to the family and to the person. The same approach is now being adopted also for People with MS needs, with the aim to offer a carefully attention to the individual needs.

At the present, two important observations may be pointed out:

1. The network approach has in the network itself its *strength*, but also its *weakness*, it means that the complexity of relationships among different entities can constitutes a deadlock with respect to the practical viability of services for the person and for the family; in many cases, document sharing is very difficult (due to privacy rules in Italy and internal management of information), the involvement of public bodies does not mean the access to large resources, but instead produces problems in fixing meetings, evaluations, activities beyond the office hours...often the resulting relationship is stressing the family members provoking a lost of trust in the overall system in place; it means a psychological problem for the future proposal of supporting programmes.

2. Reporting the MS problems to the general problem of assistance and care (as well as any other pathology) seems to be a simplified way to treat the problem: the MS is a *progressive* pathology with a degenerative path that presents problems related the physical and mental

condition of the person in a different way from any other pathology, in particular concentrating the intervention during the pousse and so during the in-hospital period of the person seems to be reductive; the public health recognises mainly this intensive intervention;

3. The Italian situation varies from region to region and within the same region the situation may differ: the network links and also some services are missing in the south of Italy instead in region Lombardia are offered also at home interventions; in this way is very difficult to describe the Italian scenario avoiding to refer to specific experiences (not necessary representative of the mean situation in Italy).

- **The proposal of AISM.**

AISM the Italian association for MS, is actively collaborating with the main social and sanitary institutions, in particular is periodically proposing issues, relevant themes and approaches. We are describing briefly the proposal coming from AISM as it is resuming a common feeling among all the associated People with MS and their families. The starting points are the need of a global approach against the pathology: covering all the issues (social and sanitary, but also wellness, solidarity, accessibility), through a network service (as already described as Italian paradigm). In this sense, the rehabilitation is a component of the service network, which is not exclusively finalised to sanitary matter, but in general working around normal living themes. Considering the present situation in Italy, the proposal is to complete the network nodes and foster the relationships among them. In this way the activities proposed could be trimmed on the regional basis (as the situation is mostly differentiated on a geographical basis).

The first point is related to the service network: as already experienced for other pathologies (ictus, oncology...), where the specialists intervention is needed in different time and places during the progression of the pathology with an interdisciplinary approach. All these supports should be part of the well-defined project around the patient and his/her conditions, this programme should be shared and approved by all the participants.

In this sense, the rehabilitation service should manage the information flux with a purposely

designed tracking system of all the patient pathway. This approach could be extended to all the social and sanitary services, as they are involved in the people with MS care as well as a central co-ordination unit thought as regional reference for the MS. This co-ordination unit should also have the objective to co-ordinate the education proposals for all the operators and assistants (in Italy there is the chance to pay and receive an accredited courses in sanitary field).

The AISM proposal points out the continuous education of personnel involved in MS care as a key factor for the success of this model. The idea is to boost the concept of overall caring of the person and his/her problems. It means that the network really works as follows:

- a general project sharing, in sense of a mutual understanding having the same goals and the same interfaces;
- the same database of patients and related needs, it means a common methodology for data survey and collection;
- to put in place protocol for the intervention of different specialists and assistants in order to form a kind of multidisciplinary unit (constituted by persons coming from different entities) able to perform a working group in favour of an effective therapeutic intervention.

An important part of this proposal is constituted by the access of People with MS to this service network: the idea is to push for the constitution of a purposely provided unit (acting as access point), in order to supply the person and his/her families well defined paths and clearly understandable options. This consideration is very important in Italy, where a consistent flux of persons is running from a region to another region in search of rehabilitation centres, often the proposed cares are superimposing the previous one adding confusion to the general discomfort of the family care givers.

This access point should be in strict contact with the provided regional co-ordination for MS interventions: it then should attain to the rehabilitation services of the Region as a part included in the sanitary plan of the region (in Italy the Ministry could be only propose the guide line for the development of the sanitary and health politics, the actual plans are developed by each region separately). This point of the proposal seems to be difficult in its practical actuation. In Italy we got 20 regions with their governments, so probably the duration of a general process, foreseeing

the putting in place this proposal, means the time for the decision for all the regional governments (in practical, different services will be put in place on geographical basis).

The last point of the AISM relation is referred to the accreditation of services for People with MS. With reference to the chance for private institutions to offer services in competition with public or public health related structure, it is very important to define criteria for the access and management of the services. Opening the "market" to the competition is normally foreseen as the way to increase quality lowering costs, in this case the concern is coming from the absence of a rigid standard that comes from the need to personalise the care/therapy. The idea is to put some criteria to reach a quality/competence level so to guarantee the assistance in a comparable way in all the centres. At present the proposal is on the table of Italian Ministry of Health, waiting for a general approval and asking for a general re-thinking of the social-sanitary network in Italy (we are now in a transition phase through a regional driven system - after the devolution - that could enhance the discrepancies in treatment and assistance among the region in Italy).

4.4. Background of the relatives of people with MS and specific training.

The charge for relatives and family in general is high in the need to re-organise the life (way of life) and the need of hours and days to assist the person with MS (refer to the number of hours lost at work in previous chapters), but these data are referred only to severe disability (normally after several years from beginning and not in all cases). On the other hand the relatives that assist a person with a good condition (low disability) do not want to prepare themselves to these problems (this behaviour was referred as a negation of the illness involving the person and the surrounding people): they do not want to be informed or prepared (in their work/life choices) to a worst period ("Why I have to think forward to this bad situation?"), they normally want to face problems day after day as they come; so there is a possible barrier in proposing educational programmes to families with PwMS in mild situation, paradoxically because the range of intervention (thinking forward) is almost good and there is enough time to proceed and prepare the environment and the service for.

The so-called "negation" is a symptom of a general feeling about the disease (mostly in recent diagnosis): it preludes to a depression state in which, mostly the person, but also the relatives, lives the situation. Normally it is hard to propose (AISM responsible interview - not reported) information except for basic info related to the disease origin and major scientific achievements: often the need of a "personalised" information/support programme is needed, de facto in caring and assistance this represents the policy of some rehabilitation centres (the therapist prepare informative sheets just trimmed on the needs and the cultural level of the family during the in-hospital period to help them returning home); the need to a personalised information (organised in sheets or separate chapters to be delivered separately) is emerging as strategy to assure the effectiveness of the project.

The way to deliver information for family care givers seems to be a critical point (more than what reveal the questionnaires), because the age and the cultural level of persons involved in caring the people with MS varies a lot; in region Umbria there are many cases in old aged families that do not have a PC and probably are not able to use it in a correct way: this type of accessibility issue (related to digital divide) could be very important in the execution of the project because it could limit the target group in a consistent way.

Coming from the last point is also the matter to simplify the language and the descriptions of the contents; the advice is to utilise (every time it is possible) figures, drawings, videos.. in order to describe visually practical operations (this is the experience of some therapist interviewed - they let to relatives personalised sheets with figures in order to explain more effectively concepts and operations with or without aids).

5. DOCUMENTARY ANALYSIS IN SPAIN

5.1. Relatives of people suffering MS. Their role.

According to data obtained in 1999, MS affects to 25000 people in Spain, and comparing with other neurodegenerative diseases, it is considered “quite common”, mostly among young women.

MS can influence the physical functions of the person and make difficult tasks that were easier before the disease. The degenerative process of this illness usually leads to a serious dependence situation in the carrying out of the most basic daily activities, such as to get dressed, to eat or to walk. Moreover, the dependence extent is higher when, besides the physical disabilities, the cognitive capacities are deteriorated at the end of the degenerative process. Other repercussion of this illness is the appearance of emotional problems (depression, anxiety, loss of self-esteem, problems for accepting the illness, etc), as it involves the need to face the gradual appearance of different disabilities.

The MS often implies a significant economical damage of the person suffering the illness and his/her family. Besides the costs that the treatment causes (medicines, technical help, adaptation of the house or apartment to the disability's needs), this disease usually appears when the person is completely active concerning working life, so the workplace absenteeism periods are very common, with the logical difficulties for the labour insertion.

As a consequence, MS involves a very important cost for the family, but not only economical. If the ill person needs help to manage to do daily tasks, it is also a great effort for the person who usually takes care of the patient. The whole family is affected by the MS since its appearance. The person suffering MS becomes dependant on anyone else, sooner or later, as the evolution of the disease can be very different from one person to another. But usually, it results in a lack of autonomy concerning physical, psychological or intellectual field, for which they need assistance or help for carrying out daily tasks. This situation involves a significant burden for the family of the person with MS, and this situation happens in the same way for the families of people with all kind of disabilities. This situation is called “Informal Support”, according to the official term established by the State for the help offered by the relatives. And more exactly, this function has traditionally fallen on the women of the family (mother, spouse, daughter, sister). In order to distinguish the

so-called Informal Support from the persons who belong to a bureaucratic structure, one of the most significant factors is that the informal career offers an altruistic support.

According to the definition made by the psychologist P. Rodriguez, the Informal Support is the care and attention dispensed in an altruistic way to the persons with any kind of disability or dependence, mainly given by the relatives, but also by other agents and services. So, according to this definition, all the attentions not given by professionals who depend to the organized social or health services would be considered Informal Support, and as consequence it is included the work carried out by volunteers and associations.

A very significant work was carried out by the Spanish Central Government with the Survey on Disabilities, Deficiencies and Health State from 1999 and during the next three years, whose results show very interesting data in the field of Disabilities in Spain.

In the table below, there are some data about the disabled people who receive personal assistance from different sources:

Source	Persons	%
Public body	123.145	6,60
Family	1.310.592	70,26
Private body	221.484	11,87
No information	209.996	11,25

Source: Survey on Disabilities, Deficiencies and Health State, 1999.

Data of 1999, referred to persons over 6 years old.

Moreover, this survey also shows the percentage of disabled people who receive help for personal assistance according to the place of residence of the career:

Careers' residence	Persons	%
Same home	1.049.195	62,81
Out home	435.283	26,06
No information	185.972	11,13

Source: Survey on Disabilities, Deficiencies and Health State, 1999.

Data of 1999, referred to persons over 6 years old.

As it can be seen in the tables above, the differences between the percentage of career at home belonging to the family nucleus are quite significant concerning the disable people, but this same situation can be applied to the specific situation of the MS.

What is very clear is that all the members of the family have to change their roles within the family system when the diagnosis of the MS comes up, although the influence of the disease is not the same for everyone. The family unit consists of persons, and each of the latter has a unique personality, needs and objectives depending on the age. This is the reason why each family member faces the illness in a different way and so has different reactions. As a consequence, it is not possible that the efforts of the family in view of the MS are made within a unified and coherent process, but the result of putting together different individual efforts to fight the disease. So, the response of a family to this disease is not an easy process.

Each family member has its own way for facing the disease. Some of them start looking for information about the MS as soon as they know about the diagnosis, and even try to talk to other people who have already had the same experience. Other relatives, however, concentrate on a variety of activities and this way they do not think about the disease. So, each person has a different way of acting in view of this situation, and it is advisable that each family member faces the disease in his/her own way, respecting the way the other members do. But faced with the changes in the activities carried out by the person with MS, the family activities change must be parallel. There are several ways to do it, and each family has to discover the most suitable for them.

The changes and evolution in the MS are continuous, and the way the family faces the situation is also very different, but there are some basic aspects that must be born in mind:

- The denial does not help, neither the desertion.
- It is crucial to understand the illness in general, the symptoms and the different evolution patterns.
- The information must be adapted to the age of the family members.
- Families can enjoy life normally, despite the illness.

However, one thing is clear: the communication is a key aspect. This way, in case the family usually faces up to common problems ignoring them or blaming another person, it is possible that is not able to combat the problem of the MS within the family. So, in this case the visit to the psychologist can be very helpful.

Finally, it must be noticed that the process of facing the illness and of adapting to it can mean a reinforcement of the family unity, and it can provide maturity to its members.

Below we describe the possible different reactions of each family member facing MS within the family environment.

Partner.

When one member of the couple has MS, it is often necessary that the couple exchanges the roles, for instance, the person who traditionally supported the family can have the necessity to assume the responsibility for the housework. It is usual that the partner feels that his/her role has become a mother/father's one, but it is necessary not to make the patient feel too dependent on the partner.

If the partner needs to assume the responsibility for the personal cares of the patient, this situation can exhaust his/her patience, mostly if there is no support from other persons. Moreover, the relationship can even risk if the ill person demands very intensive cares, such as baths, to feed, personal hygiene, etc. This way, the relationship changes and it is no more a couple close relationship, problem that can be solved with professional help.

Sometimes, the role exchange within the couple can give rise to anger and powerlessness, for which one of the most helpful solutions is to seek advice from psychologists or professional adviser. Of course, communication between the partners must be continuous, facing the factors that impede the couple to widely communicate and talk about the role exchange, how the illness has changed their daily life and how to improve their life quality.

The separation or divorce is also a situation that verifies in some cases, as the MS usually involves stress in the couple relation: the unforeseeable nature of the illness, its progression, changes, sacrifices it requires, symptoms and other aspects have influence. In these cases, the professional support, such as an adviser, can be very helpful even if the crisis is not significant, in order to continue with the open communication and to discuss the problems.

Children.

When the mother or the father has MS, it is often needed that the sons or daughters carry out certain tasks, for instance the housework. Usually, children who have grown up with a disable father or mother acquire a special sensibility and affection.

It is often noticed that when the person with MS requires cares in a quite high extent, the other members of the family are consigned to a secondary place, and this alteration affects children specially, mostly when they are little because they do not understand the situation. They sometimes feel saddened as they notice the parents do not pay attention to them as they used to.

As the children grow, the explanations given them can be more detailed: around six years old, they can understand that the ill person does not feel good all the time; about eight years old, they usually can know about the illness and make questions about it; in the adolescence they can be angry because of the deprivations and problems that the Multiple sclerosis involves.

Children usually can mean a significant help, but they also have their own fears: they are afraid of loosing their mother or father, of not being loved thinking the parents are angry with them when the truth is that he/she is tired, etc.

However, the childhood of the child must be protected, and it is advisable that some care tasks such as the personal assistance or the help for the bath is carried out by an adult, as it is not fair that children lose their childhood due to the needs of the parents. In this case, additional resources should be searched in order to avoid too much responsibility for the children.

When the son / daughter of the person with MS is a teenager, the feelings can be very strong, such as sadness, anger, shame or guilt. Most of the teenagers want to fit well in the social environment and be as their friends, and that is why they may prefer avoid talking about the situation of their mother / father. However, it is very helpful for them to tell the friends the problem from the very first moment. Moreover, the fact of having this problem at home means to make some sacrifices that the friends usually do not make (to prepare dinner, to do the washing, etc.), so it means that their responsibility at home is greater than the demands and worries their friends usually have.

Finally, MS can also have a significant effect on the professional and personal plans of the son/daughter, but the family must try to avoid it making the necessary efforts for achieving them.

Parents.

Sometimes, the person who has MS feels the need to come back to the parents' home or to have their support. If the person is used to be independent, this necessity can be quite problematic and can affect the own self-esteem, but it can be still more serious if the parents are old and have their own health problems.

Anyway, the experts advice not to protect the son / daughter excessively, as it can generate anxiety and rancour, as the parents are very worried and cannot control themselves, feeling sometimes blame for what is happening.

This situation requires also an open communication among the family members, respecting the own necessities and bearing in mind the possibility of exchanging the family roles.

In general, the first reaction of any relative of the person who has MS is to get worried because of the ignorance about the illness, because the relative has never considered his/herself as a care giver so this person needs to come to terms with a completely new situation.

All the possible consequences described above can be avoided or minimized if the family learns strategies for facing the situations and problems that come up. So, it is very important to receive external help, both psychological support and experiences exchanges with other people in the same situation, what can be done through the associations.

As conclusion of this overview of the family roles around the people suffering MS, below we show some data concerning the relation of the caregivers with the disabled person who needs assistance, taken from the Survey on Disabilities, Deficiencies and Health State from 1999. According to the figures on the chart, the most common situation is that the daughters and the partners take care for their relative with disability.

Caregiver	Persons	%
Partner	391.223	23,42
Daughter	417.163	24,97
Son	79.767	4,77
Sister	44.478	2,66
Brother	9.000	0,54
Mother	140.416	8,40
Father	12.481	0,74
Other relative	184.864	11,06
Employee	112.693	6,75
Friend	26.645	1,59
Social services	50.887	3,04
Other relation	14.863	0,89
No information	185.972	11,13

Source: Survey on Disabilities, Deficiencies and Health State, 1999.

Data of 1999, referred to persons over 6 years old.

Concerning the time these care givers spend taking care of the disabled relatives, according to data obtained from the Survey on Disabilities, Deficiencies and Health State from 1999, it usually is quite long: 41,8% of the family care givers devote more than 40 hours per week to caring tasks, and 8,8% between 31 and 40 hours per week. It means that more than the half of the family care givers carry out care tasks for a period of time that could be equivalent to a remunerated working week, and in some cases even more.

The table below shows these data in detail:

Time spent caring (per week)	Number	%
Less than 7 hours	196.245	15,3
7 – 14 hours	213.087	16,7
15 – 30 hours	206.924	16,2
31 – 40 hours	112.409	8,8
More than 40 hours	534.361	41,8
No information	16.361	1,3

Source: Survey on Disabilities, Deficiencies and Health State, 1999.

Data of 1999, referred to persons over 6 years old.

Finally, we must mention some data about the time the care givers have been carrying out these tasks: according to the Survey above, almost half of the care givers of disabled people in Spain (44,7%) have been more than 8 years doing it. Of course, it must be born in mind that as the life expectancy increases, so does the survival in dependence situations, and this is a reality that has been happening in the lasts years. Combining the time intensity and the duration of the cares, it can be deduced that there are a lot of people who cannot start working because of these duties. The table below shows the specific data about the time the care givers spend with the disabled relatives in Spain.

Years caring the relative	Number	%
Less than 1 year	77.546	6,1
1 – 2 years	136.565	10,7
2 – 4 years	212.755	16,6
4 – 8 years	265.881	20,8
More than 8 years	572.443	44,7
No information	14.205	1,1

Source: Survey on Disabilities, Deficiencies and Health State, 1999.

Data of 1999, referred to persons over 6 years old.

5.2. Support and help the relatives receive for the care of the person with MS.

People with MS need a certain extent of help and support, depending on the autonomy level and disease development. Usually, this help is provided by people who usually are around them, mostly their relatives. The problem is that, although they are interested in carrying out these tasks as well as possible, they hardly have all the necessary knowledge for that, neither the experience.

Usually, the support needed by a person with a disability or a neurodegenerative disease can be classified into three different groups of help:

- Emotional help, that is to feel loved and appreciated by the people close to her/him, to express the feelings, etc.
- Information and strategic help, that means support for the solution of problems and for facing difficult situations.
- Material or instrumental help, involving giving help or services for situations that cannot be solved by one self.

The topics of health care concerning specifically people with MS are usually the following:

- management of neurological symptoms of the disease: weakness, tremor, loss of vision, cognitive changes, sexual problems, etc.;
- home care issues and needs;
- employment issues: disclosure, job accommodations, disability insurance, etc.
- emotional and psychological issues;
- education about the disease process for people with Multiple Sclerosis and their families;
- counselling and instruction of self help;
- rehabilitation therapy exercises;
- life-planning and long term care options.

Usually, the first help the family of a person with MS receive are the primary health care centres. Here, the process of diagnosis in the Sanitary Services usually makes the patient and the family pass through several specialists, starting from the General Practitioner, who detects

the first signs of the disease. In order to get an accurate diagnosis, the carrying out of neurological tests is required, which usually take place in hospitals with a neurologist.

Relatives usually consult the professionals who treat the patient after the diagnosis, in order to get specialized extra information about the disease and the behaviour of the person with MS, as well as about how to act regarding the different topics above. It is important to know that each phase of the illness will need different professionals: neurologists, urologists, physiotherapists, psychiatrists, oculists, social workers, psychologists.

Neurologist.

The first specialist that the relative usually seeks advice and information from is the neurologist, a physician who specializes in the diagnosis and treatment of conditions related to the nervous system. This professional usually is the one who confirmed the diagnosis, and so is able to explain in detail the meaning of the illness to the patient and the family.

As in most of the cases the MS is completely new for the family of the patient, it is very advisable to have a good relation with this professional and be close to her/him in order to be able to ask any kind of information. The relatives of the person with MS will find a good support in this person.

Family doctor.

The family doctor is also a very significant person both for the patient and for the family, so it is very important to have a close relation with this professional. MS can have critical moments difficult to understand and to control by oneself, that must be dealt with every day. For this aim, the relatives must be informed about the diagnosis, forecast, treatments and adaptation to life style as the disease requires.

The family doctor is a resort that is continuously available for the care and information of the person with MS.

Physiotherapist.

It is possible that during the diagnosis process, the patient visits the physiotherapists too, in order to test some mobility problems, depending on the results of the previous tests.

Once the disease has already been diagnosed, the role of the physiotherapist becomes very significant both for the patient and for the family. In the case of the latter, this professional will help and advice the relatives for moving the patient and knowing how to act with him/her. This professional will help the family to carry out the rehabilitation of the physical impairment and to improve the movements and functions, with particular emphasis on physical mobility, balance and fatigue and pain management.

Urologist.

Majority of the patients have urinary symptoms, which can cause patient frustration. That is why it is important that the family members who usually are close to him/her get information from the urologist, as well as advice for dealing with this problems trying to reduce the shame or embarrassment of the person. Moreover, the relatives can seek advice from the urologist this can be also useful in order to know the last medical advances and treatments in this field.

Nurse.

The nurse is a key member of the patient care team, who often acts in a management and educational role teaching some skills and providing support for the rehabilitation process. The nurse is usually the link between the family and the medical staff, and it is often seen as the closest person.

It is very helpful for the family to seek advice from the nurses, as these persons are in direct contact with the patients and can offer practical advise for the daily care.

Speech therapist.

The speech therapist is specialized in the diagnosis and treatment of the speech and swallowing disorders, and a person with MS may be referred to this professional for correcting these problems.

The family members of the person with MS may be shocked the first times they notice this kind of disorders in their relative, as they will see a problem that had never seen before in a person who spoke properly. It can be very helpful for them to go to the Speech therapist in order to receive proper explanations about this problems and how to face it at home.

Occupational therapist.

The role of the Occupational Therapist is very significant for the person with MS, as this professional helps people to maintain the everyday tasks that are essential for an independent living at home and at work. The major areas targeted by the occupational therapists include upper body strength, movement and coordination (the use of assistance technology, fatigue management, work simplification, stress management, strategies for impairment in thinking, sensation and vision, etc.).

This one is a very significant person in the life of the person with MS, as it will be able to provide devices and strategies that increase the person's ability to perform activities of daily living. They can provide very important help to the family members of the patient in daily tasks such as dressing or grooming.

Diet specialist.

Although it is not proved that a special diet can help the symptoms of the MS, it usually is recommendable in order to maintain good health in general. That is why the visit to a diet specialist can be very helpful both for the patient and for the family, but mostly for the person in charge of preparing meals at home.

Psychologist

Taking into account that variety of emotional changes and experiences that MS causes on the patient, professional support and counselling is very helpful, both for the targeted person and for the family. The psychologist will provide some guidelines so that the person with MS can carry out activities enjoyed before being diagnosed with MS, as well as new interests suited to the physical changes the individual is experiencing.

Apart from the sanitary services, the public social services are usually quite requested by the families, looking for information or guidance. Moreover, the Spanish public system has also a basic service offering assistance concerning personal, psychosocial, educational, domestic and technical help both for the disabled people and for the families, making easier the possibility of continuing in their natural family environment. However, these services have the restriction of the extent of the need, so some strict requirements are asked.

Finally, we must mention the Special Centres, directed to specific types of disability, very popular in the concrete case of MS. The Spanish voluntary organizations of MS develop services concerning information and documentation, research, training for specialists, consultancy and technical assistance, both for the person suffering MS and for the family, with a lot of information that is provided for free. They also can advice about other additional organizations that offer services too, such as assistance at home. Some of them offer free telephone lines for assistance, both for the patient and for the family.

In Spain, it must be mentioned the National Centre of Personal Autonomy and Technical Help (Centro Estatal de Autonomía Personal y Ayudas Técnicas – CEAPAT), aimed at promoting research and application of modern techniques affecting all the rehabilitation aspects and at the dissemination of technological innovations that can be applied with the aim of improving the autonomy levels of the disabled people.

5.3. Entities offering the relatives support for the care tasks.

The MS, being a chronic disease, requires a continuous attention, and this attention usually goes beyond the medical field. That is why the Public Administration intends to respond to the social needs.

In Spain, when talking about the attention given to people with neurodegenerative diseases in general, we must differentiate the actuation of the Central Government bodies from the Autonomous Communities, as both of them interact in this field.

- **Central Government.**

Within the Spanish Central Government, the entity dealing with this topic would be the Ministry of Labour and Social Affairs, and more specifically, its Office of the State Secretary for Social Services, Families and Disabilities (Secretaría de Estado de Servicios Sociales, Familias y Discapacidad). This body promotes the social services, coordinates the social policies dealing with disabilities and programmes the actions aimed at the assistance and support of the disabled people. This Office of the State Secretary is divided into different entities, among which we can mention the following, as they deal with disabled people and social services.

- Institute of Elders and Social Services - IMSERSO (Instituto de Mayores y Servicios Sociales). This institution is in charge of some of the complementary services of the benefits of the Social Security system for disabled people.
- General Directorate of Social Services and Dependence (Dirección General de Servicios Sociales y Dependencia). This body, although it is mostly targeted to disadvantaged social groups, carried out the analysis, elaboration, coordination and monitoring of the action programmes concerning social services, which include disabled people.

- General Directorate of Coordination of Sectorial Policies concerning Disabilities (Dirección General de Coordinación de Políticas Sectoriales sobre Discapacidad). The target of this body is the disabled people collective, and it has the following functions:
 - To promote the sectorial policies concerning disabilities and their administrative coordination among the General Administrations between them, and with the Regional Administrations.
 - Proposal of basic rules regarding disabilities.
 - Planning and design of the programmes and plans dealing with disabilities and their coordination.
 - Promotion of the cooperation of the organizations and entities grouping people with disabilities and their families.
 - Carrying out of the State guidance concerning assistance entities and disability.
 - Relation with foreign and international entities dealing with disabilities and technical coordination or the cooperation programmes concerning disabled people.

Moreover, it must be mentioned the Royal Committee of Disability, an independent organization attached to the Ministry of Labour and Social Affairs, whose main aim is to promote the prevention of the deficiencies, the rehabilitation and the social insertion of the disabled people. It also renders support to organizations, entities, specialists and promoters concerning research, development and training.

Currently, there are some economical aids coming from the Central Government for the disabled people, processed through the Social Security, but the amount the person will receive depends on the family incomes (anyway, the upper limit is not very high).

Finally, we must mention the draft Law on Dependence, which finally will be titled “**Law on Personal Autonomy**”. This draft law is suffering delays and seems that it will not be finally discussed until autumn in the Parliament. Most of the non-profit making organizations are waiting for this text, as the measures proposed by the collectives involved included a wider catalogue of services than the current one, the presence of new technologies or social programmes for giving breaks to the relatives in the case of some diseases. According to the information the

Government has made public, this Law will promote aids for the dependent people, who are not able to manage on their own, can acquire personal autonomy, and to let citizens to have at their disposal the necessary aids for the assistance of their needs. The incomes will be the main factor, as if the users have enough resources, they will have to pay for the services needed, and if they do not have them or cannot reach a minimum amount, the social system will be in charge of the costs.

According to information got by some non-profit making organizations, it is being studied that the relatives of the disabled persons who take care of them can become self-employed and be paid by the State, but with the proof that they are really careers 24 hours per day.

- **Regional Governments.**

Most of the Social Services management belong currently to the Regional field, and the former Base Centres are a significant example of it: they are centres offering a wide range of services for the disabled people, such as services aimed at the improvement of the autonomy level and personal development, occupational or day centres, always depending on the Autonomous Community.

The subventions and economical helps dealing with disabled people that are provided by the Public Administration usually have two beneficiaries: on the one hand, the disabled people themselves and their families, so physical persons; on the other hand, legal entities, mostly centres promoting labour insertion of the disabled people through sheltered job centres.

Below we gather the most common subventions concerning disabled people given by the Regional Governments in Spain:

- Aids to the physical persons.

- Individual aids for the acquisition of technical help and barrier elimination.

- Economical assistances in favour of minors, disables and elders. It is quite usual to gather these three profiles as they are considered disadvantaged groups in the society. These aids usually comprise the following:

- direct economical help;
- domiciliary care;
- rehabilitation;
- technical help (prosthesis, etc.);
- functional adaptation of the home;
- temporary accommodation,
- professional recovery;
- transport;
- etc.

- Economical help for the adaptation and accessibility of the house to the disabled people. For these kinds of aids, it is common to ask for a minimum of 33% of handicap level or to exceed the reduced mobility scale.

- General economical subsidies for the disabled people. Usually, these calls are published annually and one of the most common requisites is to have 33% of handicap level or to be in a process that could end in handicap.

- Economical aids for support in the autonomy at home. There are some helps for the disabled people who want to live alone or with the partner and need a certain support. Moreover, in some Regional Autonomies, such as Catalonia or Madrid, there are Technical Assistance Centres where the disabled person can receive advice for technical help or for the adaptation of the own home, information for the adaptation of the communication means, as well as dissemination and exhibitions of the different techniques.

- Economical aids aimed at promoting the staying of the disabled person in the family and social environment. The Regional Government of Catalonia, for instance, had last year a programme called "Living among family" whose beneficiaries were disabled people with a 75% or higher handicap level and whose dependence on another person was continuous.

- Social assistance for people with disabilities in general (with the requisite of at least 33% handicap level or children younger than four whose development is suffering a delay, according to the evaluation of the technicians). This assistance can include the following topics:

- assistance in the treatments (speech therapy, rehabilitation,...);
- domiciliary care;
- transport;
- technical help for communication;
- etc.

- Economical aids to disabled people who want to become self-employed. A significant example can be found in the Regional Community of Galicia, as the Regional Government offers economical support for the disabled people who want to develop an own business project.

- Aids to the legal entities.

- Economical aids for the public and private bodies and associations, aimed at the creation and maintenance of the jobs of disabled people, as well as for the creation of sheltered job centres.

- Public economical aids to public and private companies, sheltered job centres and non-profit making organizations, for the creation of new jobs for these people within the centres and the promotion of recruitment of disabled people in the companies.

- **Local Administrations.**

Moreover, the local administrations have also competence for it, being the most known programmes the following:

- Assistance to disabled people in Social Services Centres (information, guidance, processing of applications for gaining admittance to Daily Centres and Occupational Centres, labour advising).
- Home help Service: help at home for daily tasks.

Finally, the Spanish Government has published the White Paper on Dependence, where some of the most significant aspects of the social services for people who need the help of the others are explained. Among a wide range of topics, problems and solutions it analyses the needs of the care giver families, stating that it is necessary to develop specific programmes directed to the families, through the so-called “to take care of care givers”, with the general aim of reducing or modulating the burden of the care giver.

Some of the challenges in order to improve the social services for the families of the dependent people concern the following areas: cognitive aspect (to modify previous ideas about the illness), psycho-affective aspect (to interpret emotions, solution of depression and anxiety problems), relationship aspect (to improve the quality and quantity of the relations), instrumental support (domiciliary service, social support networks), free time (to improve the recreational atmosphere), organizational aspect (to help planning and execution of the daily activities).

The current programmes and measures for the relatives of disabled people in Spain concern information, guidance and advise about the general cares given the dependent person for the families, usually offered by the social workers or nurses.

We would like to mention the so-called “intermediate services” are assistance services whose main aim is to affect positively any of the dimensions that can create the stress of the care giver and to reduce the negative aspects of the care.

But the truth is that all these measures are not effective enough for the real needs of the families, and they usually get most of the support from the associations of relatives of people in

dependence situation (one of the most known in Spain is the association of relatives of people suffering Alzheimer). The associations have often made up for the lacks of the Public Administrations with these types of programmes.

5.4. Background of the relatives of people with MS and specific training.

As a consequence, we can state that there is no specific training for the relatives of people with MS on how to take care of the patients. They usually learn it with the practice, day by day, through some kind of self-training using mostly the following means: books, documents, brochures, magazines, Internet, group meetings or conferences.

The guidance the relatives received from the professionals mentioned above is one of the most significant support for the family of the person with MS, but it cannot be considered as training, as there are a lot of needs that are not covered with them.

Thus, the relatives feel lost in some situations, as they do not know how to face some symptoms of the disease. For this aim, a training covering all the necessary aspects of the MS could be very useful for them, as there is nothing specially addressed to them.

B. QUANTITATIVE RESEARCH

1. INTRODUCTION

Here we present the results of the Quantitative research carried out in the countries participating in the project QUALIFIED CARE: Czech Republic, Greece, Italy and Spain. The research has been carried out through questionnaires distributed among relatives of people suffering MS who take care of them.

The aim of this research has been to get to know the training level of these people and their needs concerning the caring tasks they usually carry out for the patient.

On the basis of the results of this research, together with the results of the Qualitative research, a Training Tool for the relatives of people suffering MS will be elaborated in the framework of the project QUALIFIED CARE.

For the execution of this research, a model of questionnaire was designed and translated into all the languages of the partner countries. The questionnaires had a specific structure, as they were divided into four sections as follows:

1. Personal data.
2. Data regarding cared person with MS.
3. Social & labour data.
4. Data regarding the care given and training level.

Firstly, we will see the results obtained in each participating country, and secondly, we will analyse the results globally.

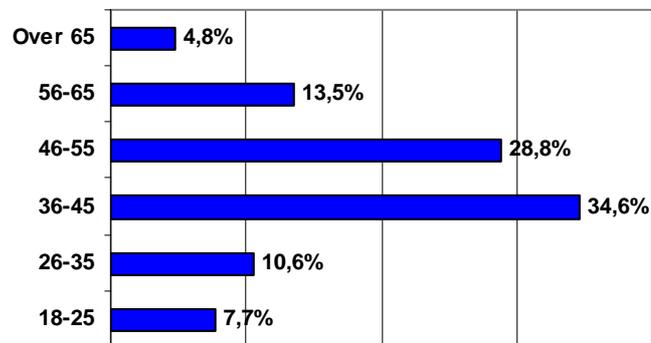
2. QUANTITATIVE RESEARCH IN CZECH REPUBLIC

2.1. Personal data.

In all, 105 questionnaires were completed in the Czech Republic, distributing them among different cities of the country.

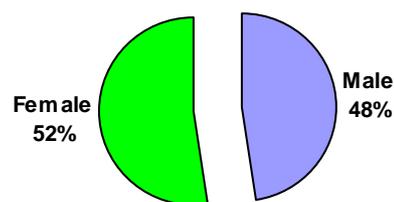
Concerning the personal profile of the participants, majority of them were between 36 and 55 years old (63.4%), as it is shown in the graph below: Thus, it is considered that they are in the proper age for being active in the labour market.

Graph 1: Age



The gender of the relatives that cared the person with MS is shown in the Graph 2, where a slight difference can be seen between men and women: 52% female and 48% male.

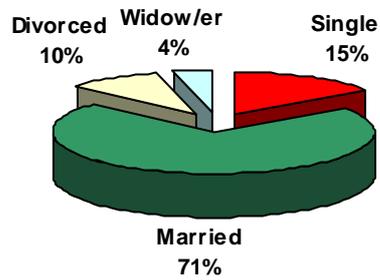
Graph 2: Gender



The marital status and the educational level of the participants are shown in Graphs 3 and 4, respectively.

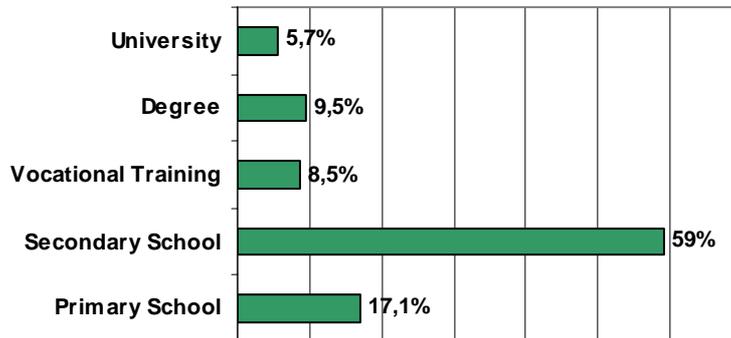
Concerning the first topic, most of them were married (71%), with a big percentage.

Graph 3: Marital status



As far as the educational level of the participants is concerned, majority of them had the Secondary School degree (59%), followed by those with the Primary School one (17.1%). It must be mentioned that among most of the people belonging to the 5.7% of University Degrees specified they were engineers.

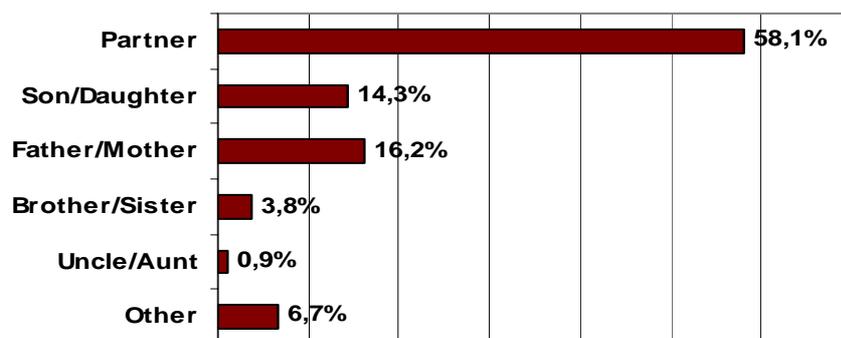
Graph 4: Educational level



2.2. Data regarding cared person with MS.

As established in the project, the target group of QUALIFIED CARE is formed by the relatives of people with MS who take care of them, and the same profile was required for the participants in the Quantitative research. According to this requirement, different relationships were possible among the participant and the person with MS. The percentages of those in the Czech republic are shown in the Graph 5: a great majority (58.1%) were partners of the person with MS, both married and not. The next percentage concerned the parents of the patient (16.2%) and the third one the sons or daughters. Concerning the item "Others", it must be noted that all of them took care of one good friend, and it was considered as if it was a family relationship too.

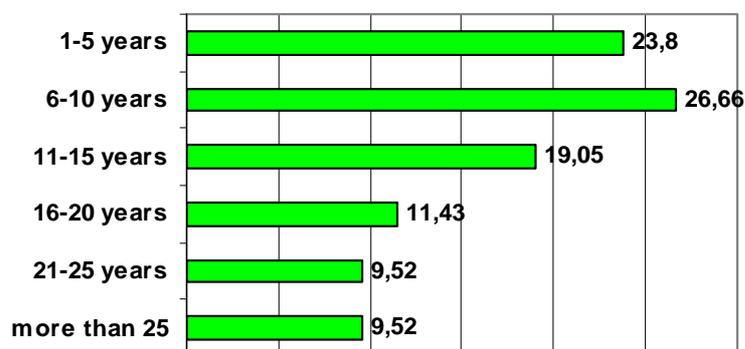
Graph 5: Relationship with person with MS



Next question dealt with the antiquity of the disease of the persons suffering MS cared by the participants since the diagnosis, directly linked with the next one, which asked them about the autonomy level of the patient. Results of both items are presented in Graphs 6 and 7, respectively.

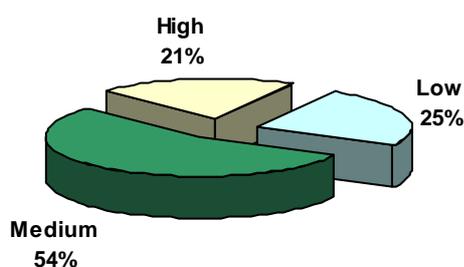
Concerning the years of disease of the cared persons with MS, it was quite balanced: 26.66% of them had had it for 6-10 years, followed by those whose diagnosis had been quite recent: from 1 to 5 years, 23.8% of the participants. 19.05% of the participants were taking care of their relatives who had been ill for 11-15 years, 11.43% for 16-20 years, 9.52% for 21-25 years, and finally 9.52% for more than 25 years.

Graph 6: Years of disease of person with MS (%)



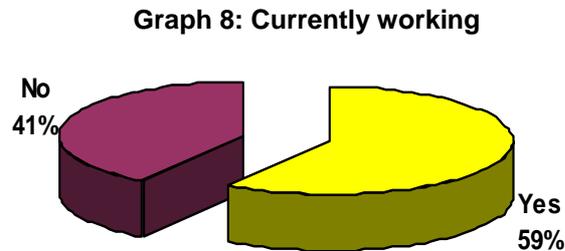
Regarding the autonomy level of the persons with MS cared by the interviewees, majority of them had medium autonomy level (54%), it means needing assistance from persons or technical means in specific moments; 25 % had low autonomy level, so the patients needed permanent assistance from persons or technical mean, and finally the lowest percentage (21%) was formed by those with a high level of autonomy, it means persons who does not need assistance from persons or technical means.

Graph 7: Autonomy level of person with MS



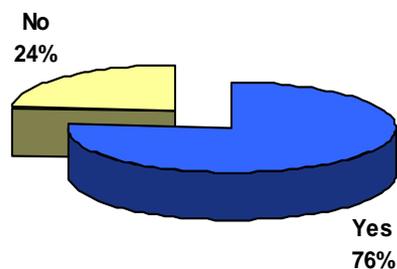
2.3. Social & labour data of the interviewees.

The participants were asked whether they were working or not, and the answers are shown in the Graph below. More than half of them were working at that moment (59%) and 41% were not.



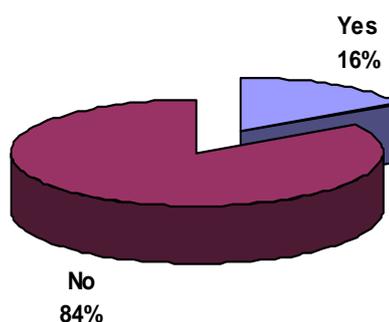
Just after this question, they were asked if they worked before the MS diagnosis of the relative, to which 76% answered affirmatively. Linking Graph 8 with the one below, it involves that before the diagnosis there was a 17% of people working who have left it after the diagnosis.

Graph 9: Working before the diagnosis



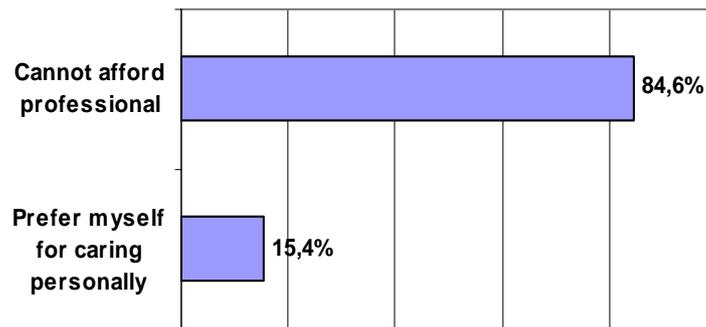
Moreover, those who answered that they were working before the MS diagnosis of the relative, were also asked whether they left the job for taking care of the person with MS, and the results are gathered in Graph 10. Most of them answered negatively (84%), so only 16% of them did it.

Graph 10: Left work for caring person with MS



The reasons why this group of people represented by the 16% left the work and decided to devote themselves to take care of the relative with MS was mostly that they could not afford paying a professional for doing it (84.6%), and 15.4% preferred to take care of the relative personally.

Graph 11: Yes - Reasons

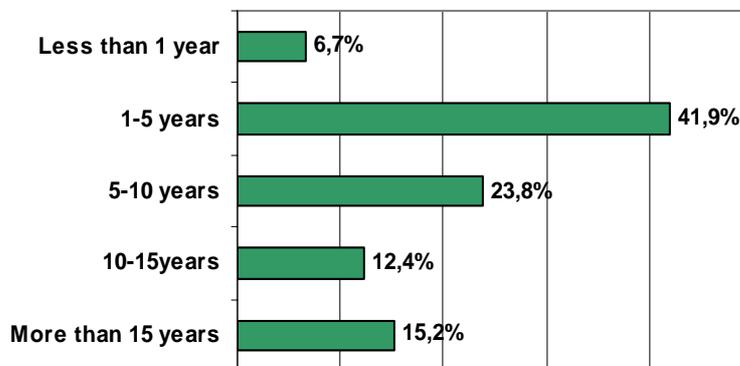


2.4. Data related care given and training level.

Next section of questions dealt with the care given by these persons to the relative with MS and the educational background for it.

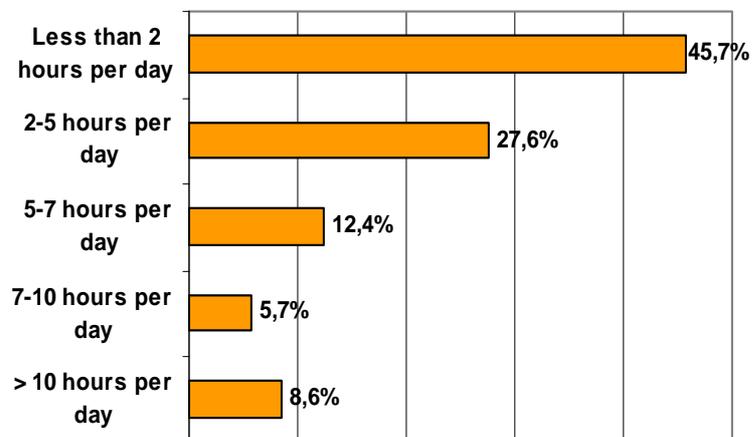
Thus, the first question was intended to know for how long they had been taking care of the person with MS, whose results can be seen in the Graph below. The majority group was between 1 and 5 years of care in the past (41.9%), followed by those between 5 and 10 years (23.08%).

Graph 12: How long taking care



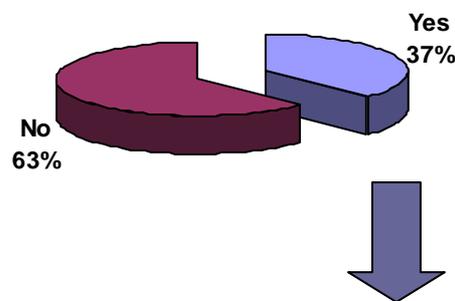
Next question asked them how much time they usually devoted to the care of their relative, and the main percentage was for those who did it for less than 2 hours per day (45.7%), followed by those who devoted from 2 to 5 hours per day.

Graph 13: How much time per day

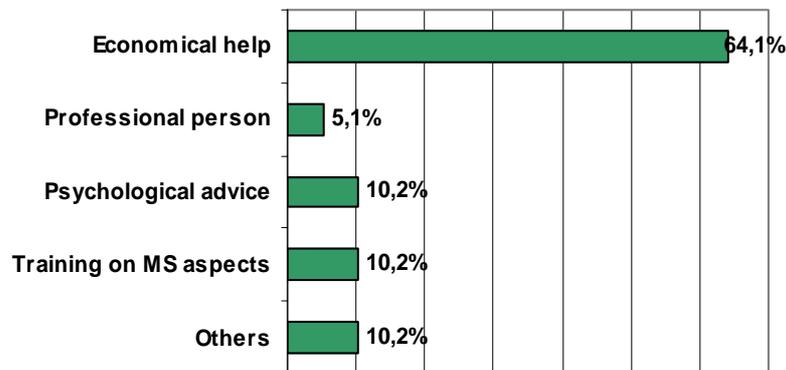


Concerning the support the interviewees received for the care of the relative with MS, 63% of them said that they did not get any support for this aim, and only 37% said they received some support. As consequence, we asked all those who effectively got some support, what kind of support it was and where it came from. As it can be observed in the Graph 15, most of them (64.1%) received economical help fro that task, and only some of them got some training, psychological advice or a professional person for helping them.

Graph 14: Support for the care

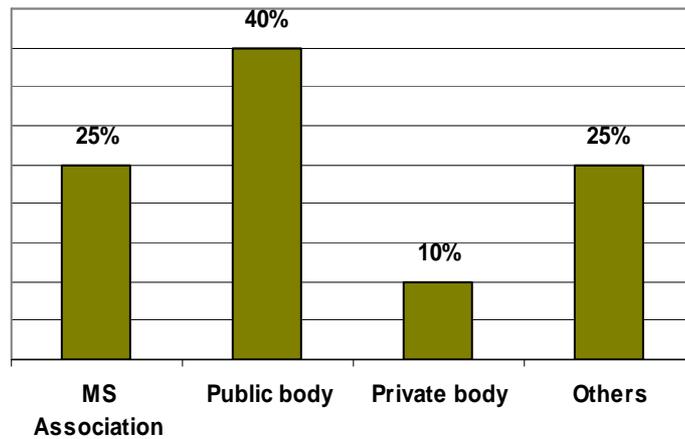


Graph 15: Kind of support



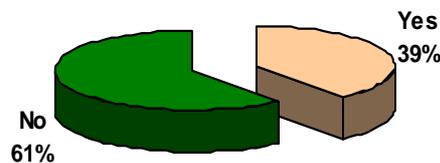
As far as the origin of this help is concerned, Graph 16 shows that in most cases it was coming from a public body (40%). Moreover, in some cases they got support from MS associations (25%), private bodies (10%) or other kinds of support (family support, mainly).

Graph 16: Support coming from



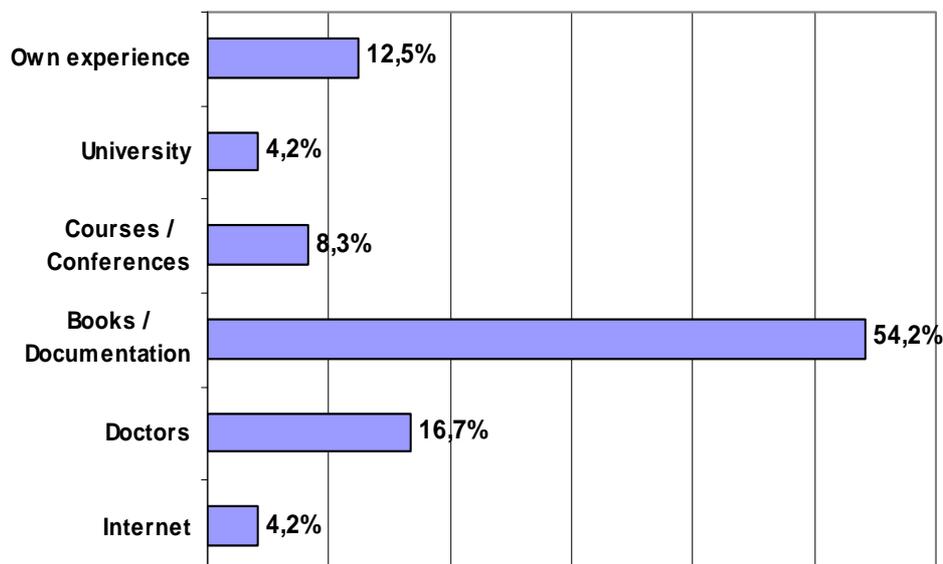
Next, we asked the participants whether they had specific knowledge on MS patients' needs, and we saw that majority of them did not (61%), as it is shown in Graph 17.

Graph 17: Knowledge on MS patients' needs



Only 39% of them said they had some knowledge, but it was asked them where and how they acquired it, whose answers are in the Graph 18 shown below.

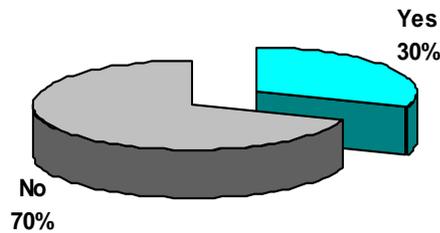
Graph 18: Where and how acquired



Most of them had acquired the knowledge through consulting books or documentation (54.2%), followed by those whose knowledge was offered by the doctors (16.7%). The own experience was the third possibility (12.5%), the attendance to courses or conferences was also considered a way of acquiring knowledge for some of them (8.3%), and finally the University and the internet for 4.2% each of them.

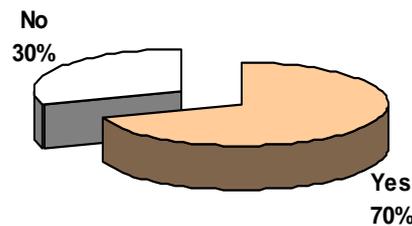
Next questions were about the difficulties they found during the care tasks with their relatives with MS. Only 30% of them admitted they indeed had them

Graph 19: Find difficulties during care tasks



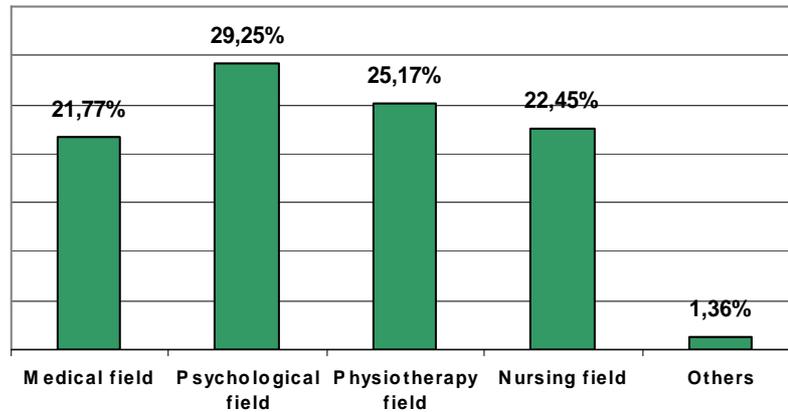
However, when asked whether they considered they needed to acquire any specific knowledge for caring the relative with MS, a great majority of them (70%) answered affirmatively.

Graph 20: Need to acquire specific



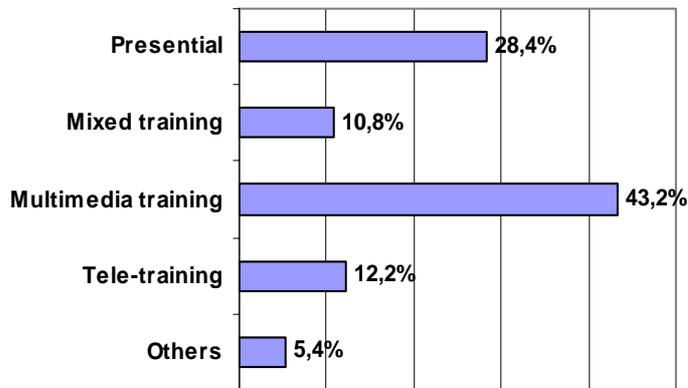
Concerning the fields they thought the need was most significant, the first one was the psychological aspect (29.25%), followed by the physiotherapy (25.17%), the nursing (22.45%) and finally the medical field (21.77%), as it can be seen in the Graph below.

Graph 21: Yes - Fields



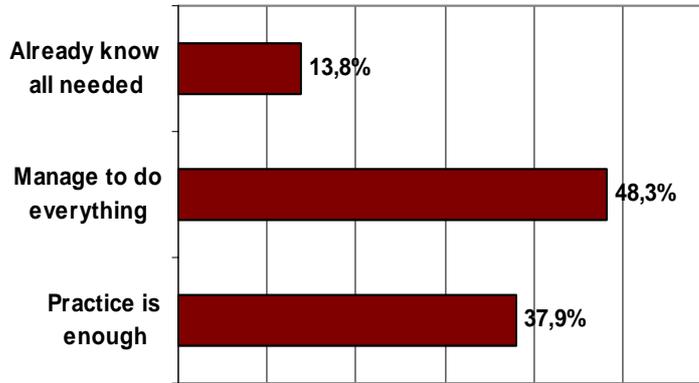
The most suitable method for receiving training in the fields above explained would be, according to the participants' opinions in the Czech Republic, the followings: the first choice would be the multimedia training (43.2%), followed by the presential one (28.4%), it means in a classroom with a teacher and other students.

Graph 22: Yes - Most suitable method



On the other hand, those who answered negatively to the answer of Graph 20 (who represented only 30%), stated as main reasons the ones listed in the Graph below. The most common reason was that they already managed to do everything without receiving additional training (43.3%); the second one was that the practice was enough and they did not need theoretical training (37.9%), and finally, because they already knew all they needed (13.8%).

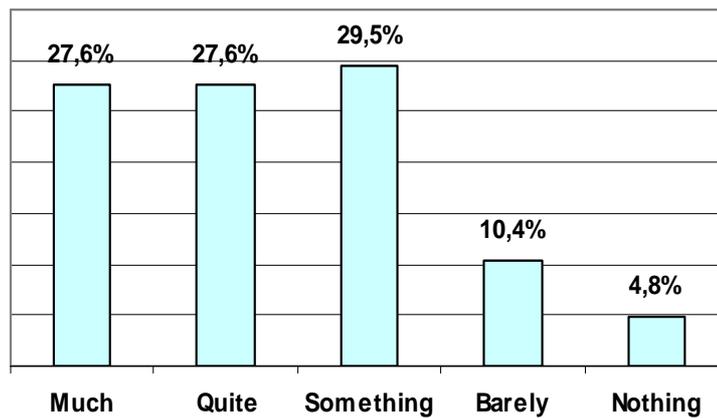
Graph 23: No - Reason



Finally, all the participants were asked about their opinion about the extent the training in some fields would improve the quality of the caring tasks for the person with MS, and the results were quite diversified, as it can be noticed when looking at Graph 24:

The first opinion was that it would improve it something (29.5%); second and third opinions obtained the same percentage, for those who think it would improve a lot and quite. So, in general the answers were quite positive.

Graph 24: Training would improve the care



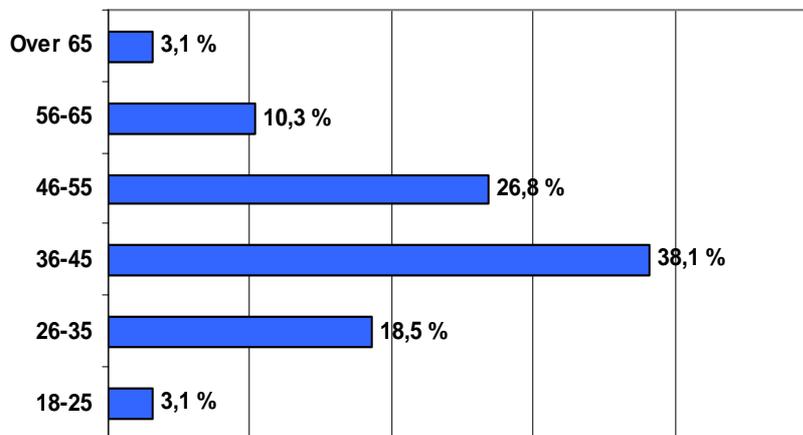
3. QUANTITATIVE RESEARCH IN GREECE

3.1. Personal data.

In all, 100 questionnaires were completed in Greece, distributing them among two cities of the country: Patras and Thessaloniki.

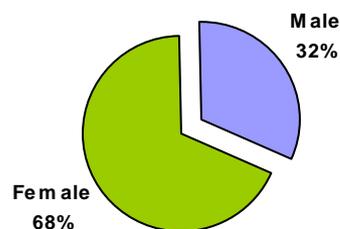
Regarding the participants' personal profile, the age was the following: as shown in the Graph 25, most of them (38.1%) were between 36 and 45 years old, followed by those who were between 46 and 55 (26.8%).

Graph 25: Age



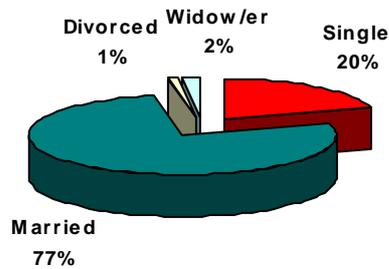
As far as their gender is concerned, majority of them were women, as in most of the counties of the research.

Graph 26: Gender



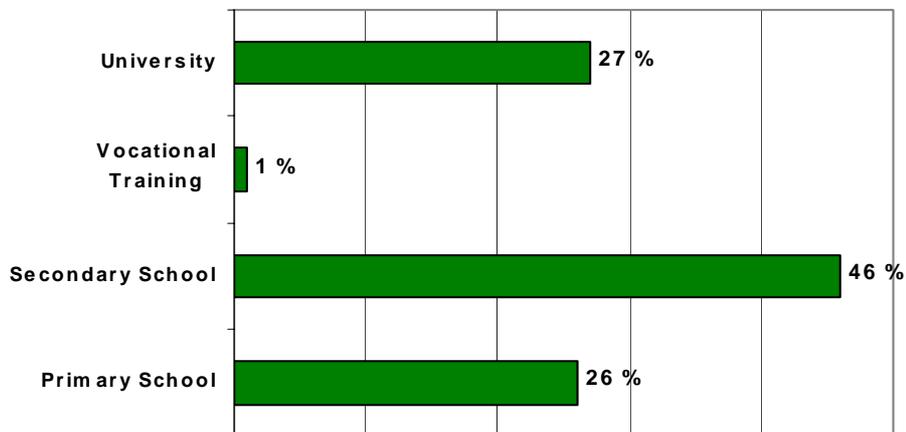
Most of them were married (77%), as can be seen in the Graph below, and it was followed by those who were single (20%).

Graph 27: Marital status



As far as their educational background is concerned, almost half of the participants in Greece had the Secondary School degree (46%); this percentage was followed by those who had attended the University (27%) and by those with Primary School degree (26%).

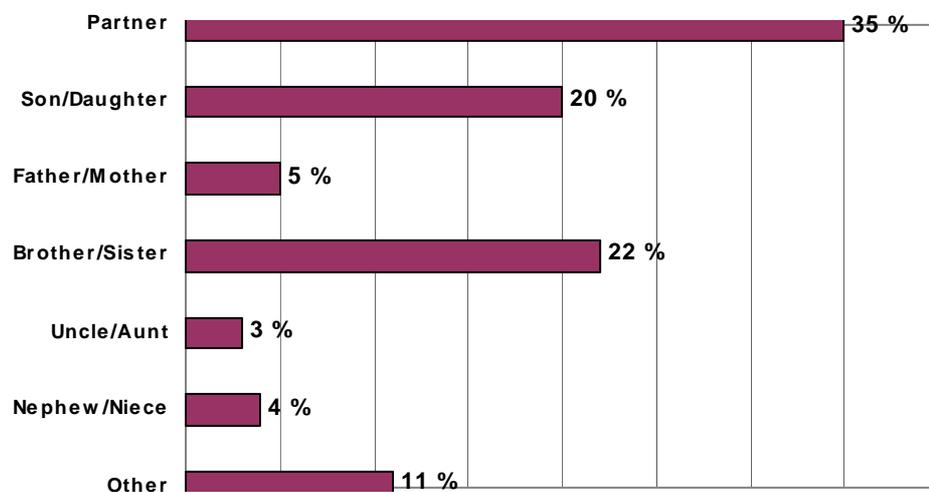
Graph 28: Educational level



3.2. Data regarding cared person with MS.

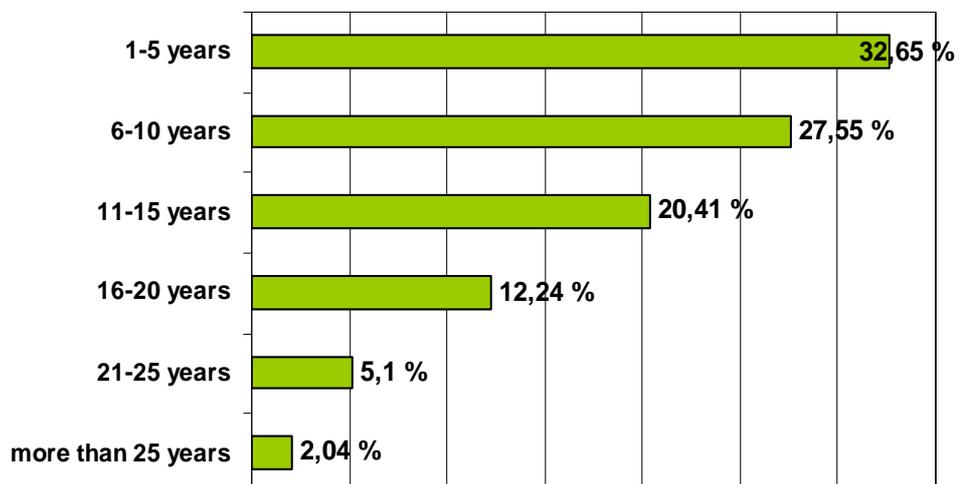
Majority of the interviewed persons who took care of the persons with MS had with the latter a relation of partnership (35%), followed by those that the patient was their brother or sister (22%) and son or daughter (20%). It must be pointed out that the percentage of 11% "Other" was completed by those who said that were taking care of their best friend with MS, the brother/sister in law and cousin.

Graph 29: Relationship with person with MS



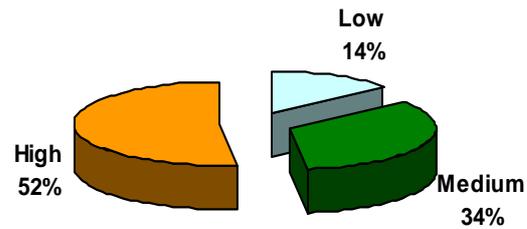
Regarding the disease of the patient with MS, we can notice that in general they have not had it for a long time, as it can be seen in Graph 30: 32.65% had had it for 1-5 years, 27.55% for 6-10 years, 20.41% for 11-15 years, 12.24 for 16-20 years, 5.1% for 21-25 years and 2.04% for more than 25 years. So, as we can see, higher the percentage it is, lower the antiquity of the disease.

Graph 30: Years of disease



As a consequence, the autonomy level of the patient is, in most of the cases, quite high, as it is shown in the Graph below, where more than half of the participants' relative with MS have high autonomy level (52%), which means that does not need assistance from persons or technical means.

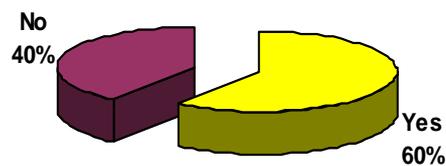
Graph 31: Autonomy level of person with MS



3.3. Social & labour data of the interviewees.

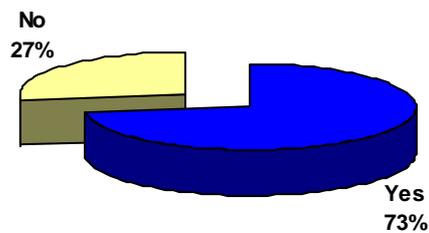
Most of the interviewed persons in Greece were working at the moment of the questionnaire, 60% of them, as it is shown in Graph 32. It can be also linked with the high autonomy level of the patients (Graph 31), which means that the relative does not need to assist the person continuously.

Graph 32: Currently working



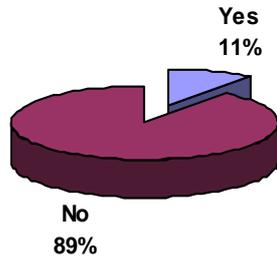
In the Graph below, we can see that majority of the participants were working before the diagnosis, 73%. So we can deduce that 13% of the interviewees were working before the diagnosis of their relative and gave it up once they got to know it.

Graph 33: Working before the diagnosis



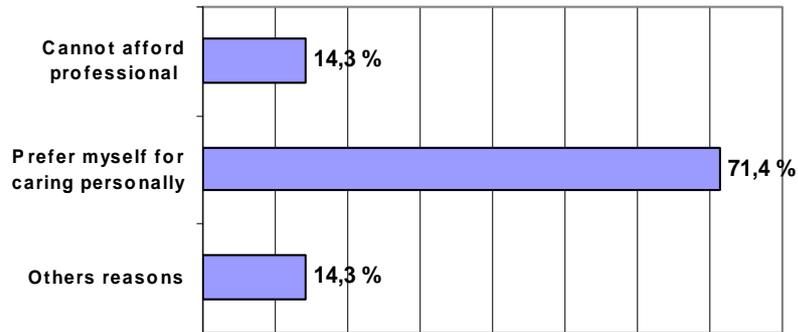
Moreover, we asked this 73% of people whether they left the job for taking care of their relative with MS, and only 11% said so. 89% of them said that the illness of the relative was not the reason why they left the job.

Graph 34: Left work for caring person with MS



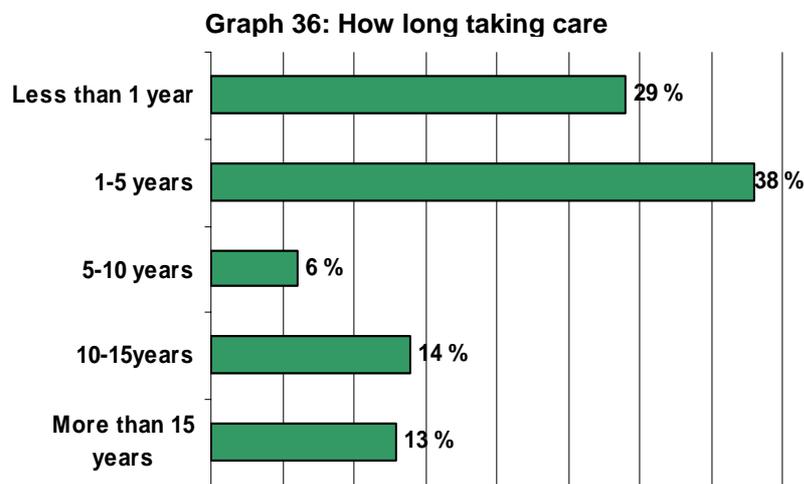
The specific reasons that the 11% claimed were the following: most of them preferred to take care of the person with MS personally (71.4% said so); some of them said that it was because they could not afford a professional for taking care of the patient, as well as other reasons.

Graph 35: Yes - Reasons



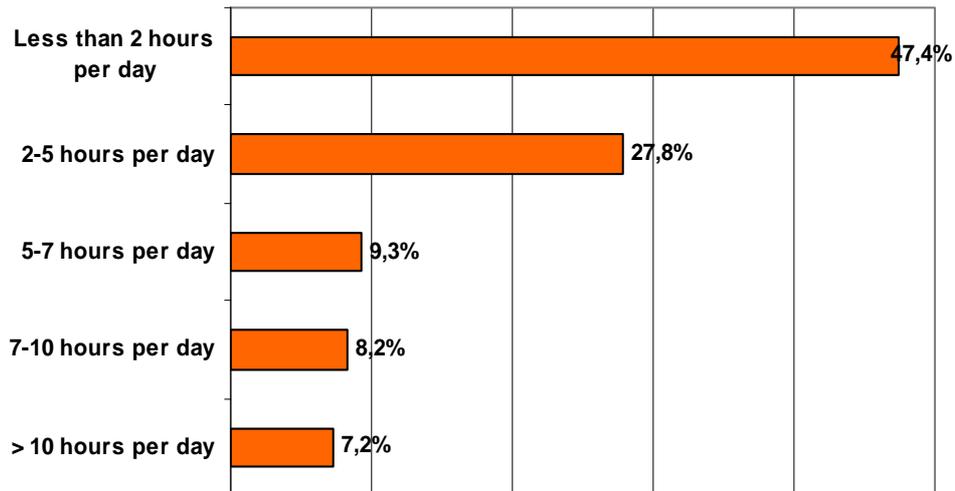
3.4. Data relating care given and training level.

The participants in Greece had not been taking care for their relative with MS for such a long time as in the other partner countries, which is directly linked with the results shown in Graph 30 (years of disease of the patient). As we can notice in the Graph below, majority of them had been taking care of the ill person for 1-5 years (38%), followed by those who have taken care of him/her for less than one year (29%). So, those who have taken care of the patient for less than 5 years add up to 67% of the total in Greece.



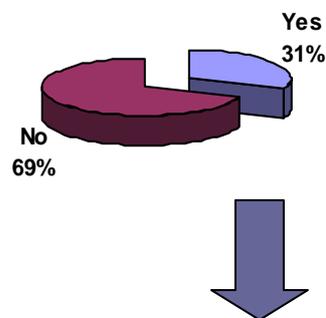
The results of the next question are also linked to the ones in Graphs 30 (years of disease) and 31 (autonomy level of the patient). In the Graph below we can see that almost half of the persons (47.4%) took care of the patient with MS for less than 2 hours per day, and this percentage is followed by the one of relatives who usually do it for 2-5 hours per day (27.8%). In general, the dedication is not for so long, and this is a direct consequence of the high autonomy level of the patients chosen in Greece for the research.

Graph 37: How much time per day

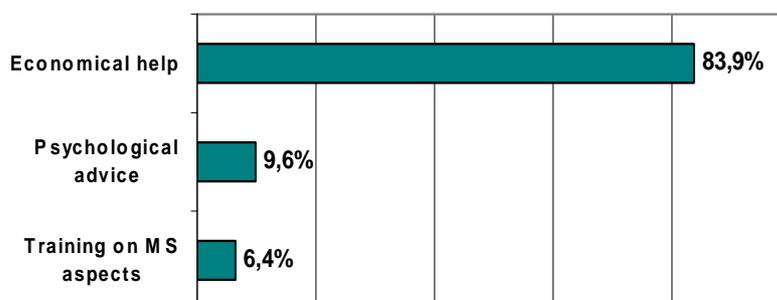


69% of the participants did not receive any support for taking care of the person with MS; only 31% did it, as shown in Graph 38. The most common support that the latter percentage received was economical one (83.9%); some of them got psychological advice (9.6%) and training n MS aspects (6.4%). All the latter are gathered in Graph 39.

Graph 38: Support for the care

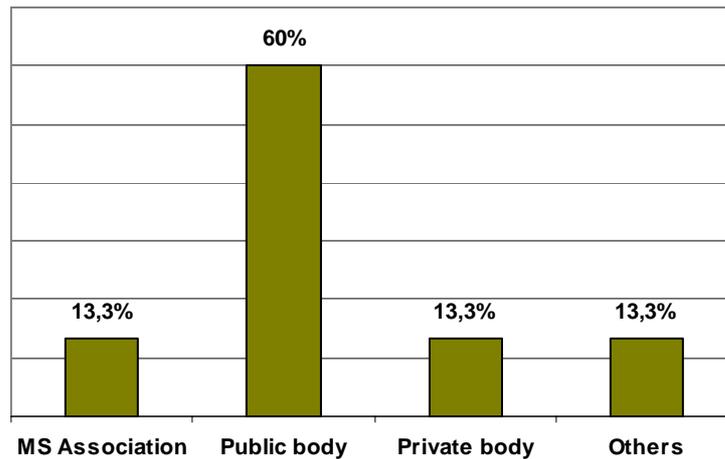


Graph 39: Kind of support



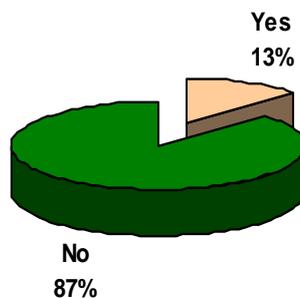
Moreover, these supports, in majority of the cases, came from public bodies (60%), as shown in Graph 40. MS associations and private bodies gave supports also, but at a lower extent. The item others gathered family support, volunteers and hospitals.

Graph 40: Support coming from

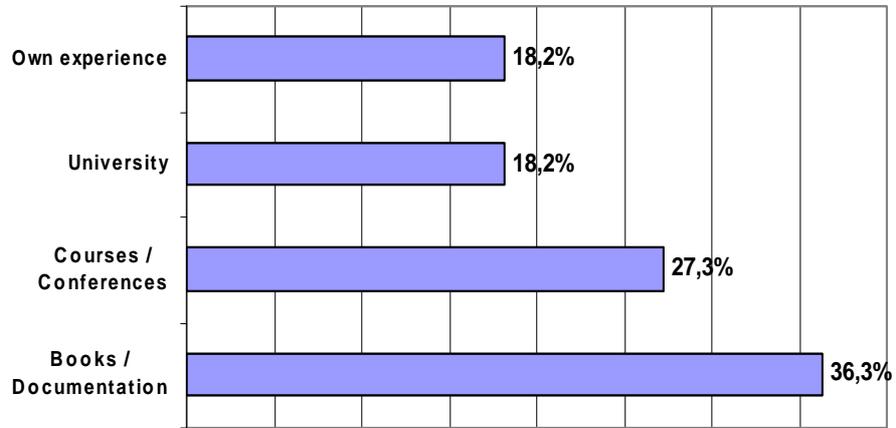


A great majority of the interviewed people in Greece did not have any type of knowledge about the MS patients' needs (87%), only 13% said they had, as it is shown in Graph 41. This percentage of people acquired the knowledge through the means shown in Graph 42: most of them did it through books and documentation (36.3%), followed by those who did it attending courses or conferences on the subject. Moreover, 18.2% learnt it through the personal experience, and the last 18.2% of the participants acquired that knowledge at the University (nursing or medical studies).

Graph 41: Knowledge on MS patients' needs

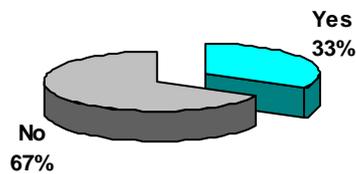


Graph 42: Where and how acquired



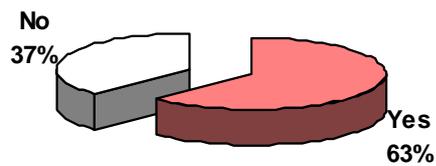
Although majority of the participants said they did not have specific knowledge about patients' needs, most of them considered did not face difficulties during the caring tasks (67%).

Graph 43: Find difficulties during care tasks



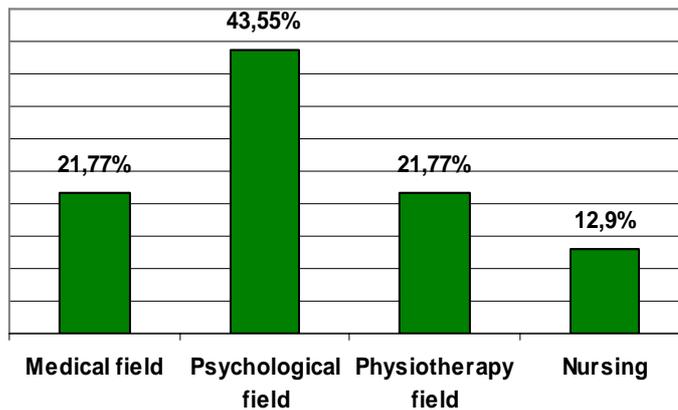
However, Graph 44 shows that majority of the participants from Greece thought agreed on the need to acquire some specific knowledge for taking care of the relative with MS (63%).

Graph 44: Need to acquire specific knowledge



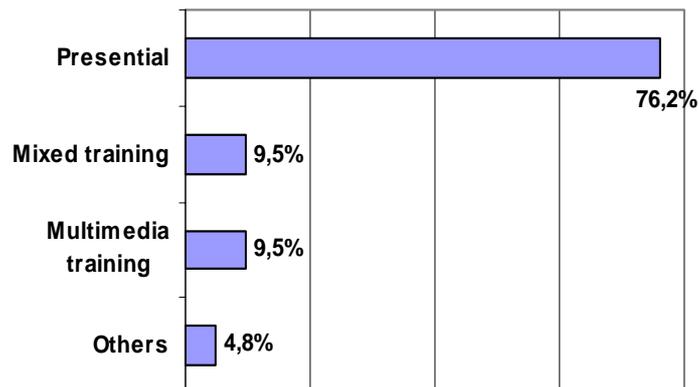
The fields in which they consider they need to acquire knowledge are the following: firstly, the psychological field (43.55%), followed by the physiotherapy and medical fields, both with the same percentage (21.77%), and finally the nursing field (12.9%).

Graph 45: Yes - fields



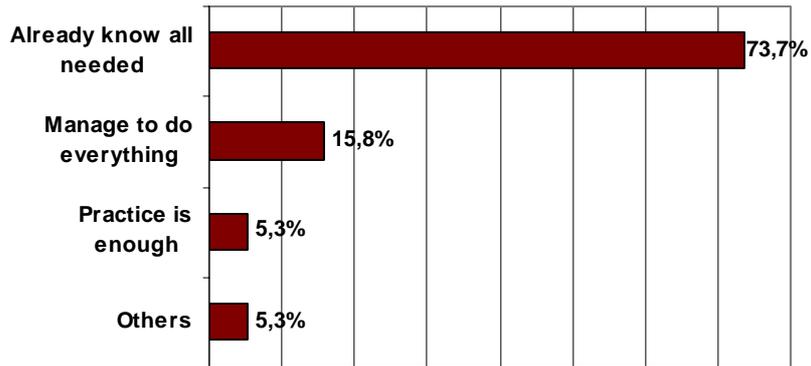
For acquiring this knowledge, the participants thought that presential lessons would be the most suitable method (76.2%), it means with teachers and pupils in classrooms. The mixed training and the multimedia training were not very popular, as each of them was chosen only by 9.5% of the participants.

Graph 46: Yes – most suitable method



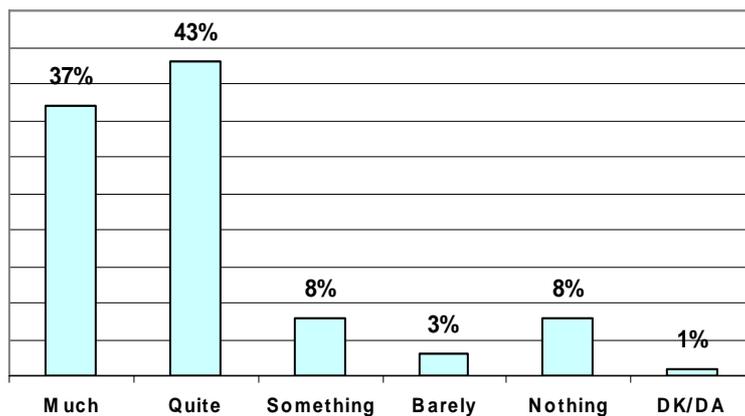
On the other hand, those who said they did not need to acquire specific knowledge for the care, said that it was mostly because they already knew all they needed for the caring tasks (73.7%); some of them argued that it was because they already managed to do everything that way (15.8%), and finally a few of them said that the practice is enough for that (5.3%).

Graph 47: No – reasons



Finally, last question was about the efficiency of the training for the improvement of the caring tasks quality, and the perception of the participants was quite positive, as it can be seen in the Graph below: 43% of them said that training would improve it at a quite extent, and 37% said that it would improve it much, so we can say that 80% of the participants took it as something positive.

Graph 48: Training would improve the care quality



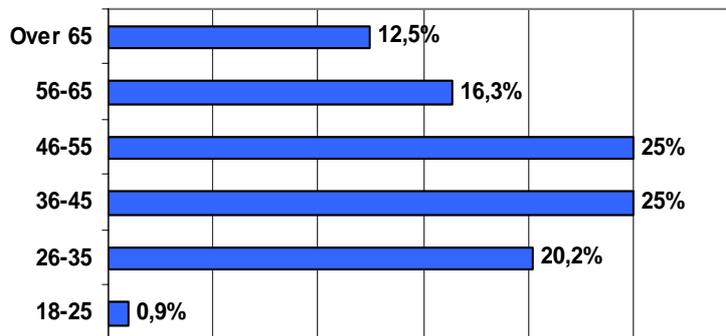
4. QUANTITATIVE RESEARCH IN ITALY

4.1. Personal data.

In Italy, 100 hundred questionnaires were carried out among relatives of people with MS who take care of them.

The age of these relatives was in the proportions shown in the Graph below:

Graph 49: Age

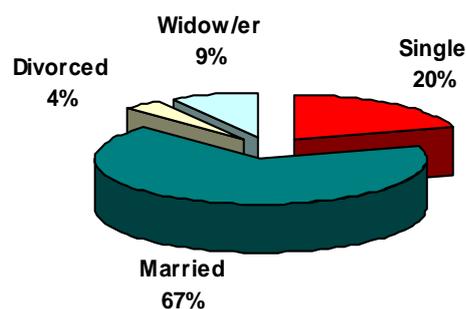


In Italy, just like in the other countries analysed in this report, majority age group of the participants was between 36 and 45 years old (25%) and between 46 and 55 years (25%). So, half of the participants were between 36 and 55 years old. We can notice a slight difference from this country to the others, as in the other countries the percentage of participants of this age was higher.

Participants in Italy were 50% women and 50% men, what is different from the other countries, as in all of them the women were majority.

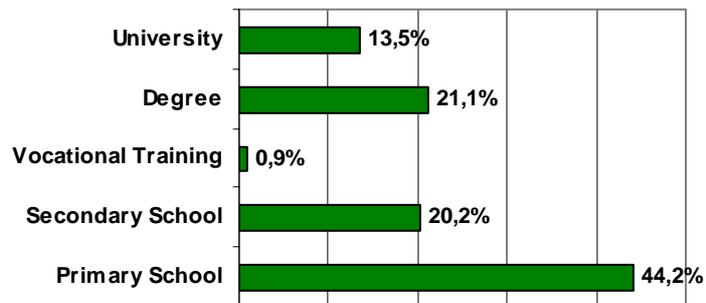
Concerning the marital status, 67% of the participants were married, followed by the singles with the 20%. Graph 50 shows the results.

Graph 50: Marital status



Last question concerning the personal data of the participants was about the educational level, where the majority percentage was the Primary School degree (44.2%).

Graph 51: Educational level

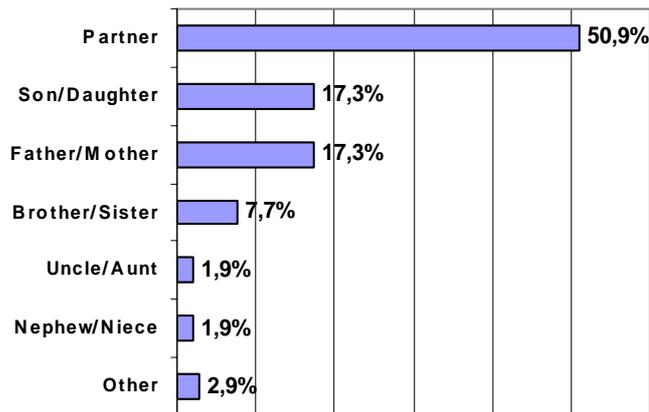


It must be pointed out that, concerning the University degree (13.5%), most of them said that it was Medicine, followed by the Nursery and Psychology.

4.2. Data regarding cared person with MS.

In Italy, half of participants were the partner of the person with MS (both married and not), more exactly the percentage of 50.9%. The next two items were those whose son/daughter and father/mother were the patients, both of them with the percentage of 17.3% each.

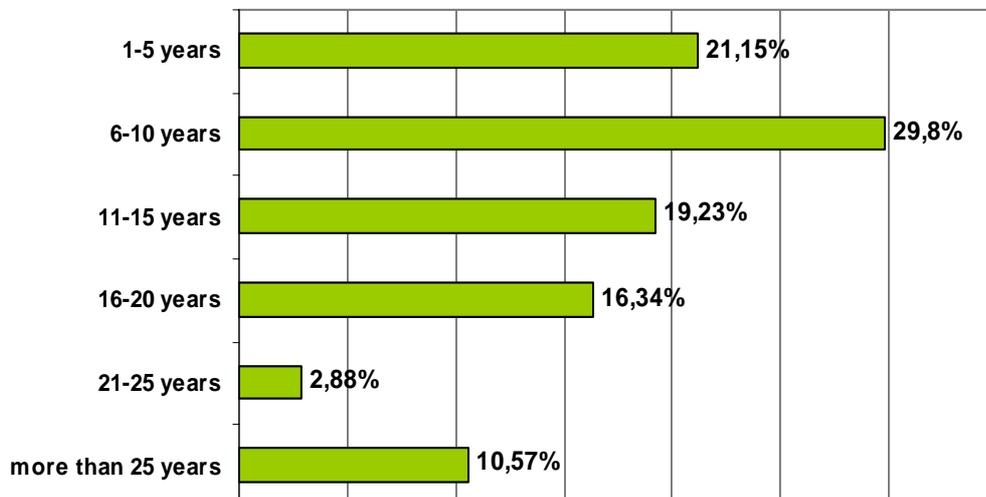
Graph 52: Relationship with person with MS



The item "Other" (2.9%) included friends that were cared by them.

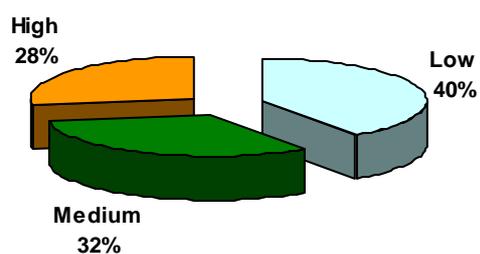
Graph 53 shows the information about the years of the MS disease of the care person, and majority of them (29.8%) said it had been for 6-10 years (29.8%). Those whose relatives had had the disease for 1-5 years were 21.15%, so in this country the antiquity of the disease has not been for so long.

Graph 53: Years of disease of person with MS



Most of the participants' relatives with MS had a low autonomy level (40%), what means that the needed permanent assistance from persons or technical means; this percentage was followed by those who had medium autonomy level (32%), who needed assistance from persons or technical means in specific moments; and finally, those whose autonomy level was high represented only the 28% of the participants.

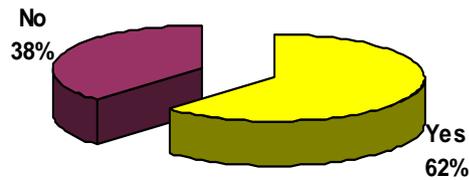
Graph 54: Autonomy level of person with MS



4.3. Social & labour data of the interviewees.

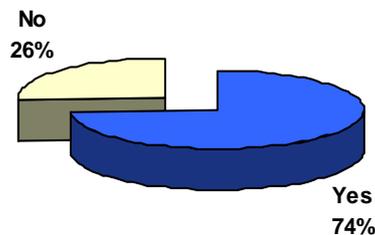
Concerning the information about the participants' social and labour situation, most of them were working when the questionnaires were carried out (62%).

Graph 55: Currently working



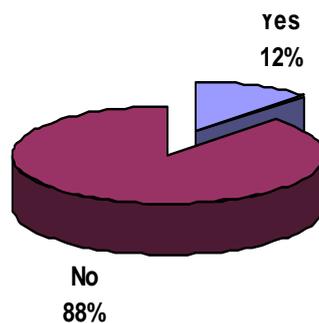
Moreover, when asked whether they were working before the diagnosis of the relative, 74% said they were indeed (Graph 56). So, taking a look at Graphs 55 and 56, we can deduce that 12% left the job after the diagnosis of the relative.

Graph 56: Working before the diagnosis



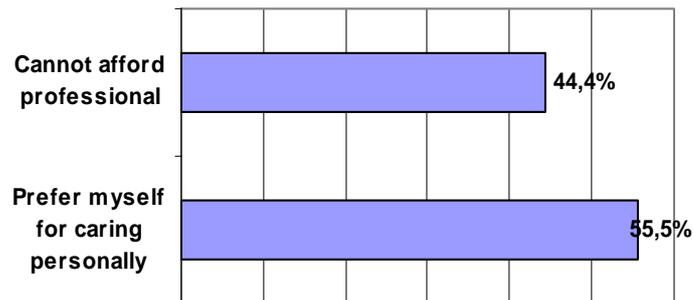
Those who said they were working before the diagnosis of the relative were asked if they left the job for taking care of the ill person, and most of them answered negatively (88%), as it can be seen in Graph 57.

Graph 57: Left work for caring person with MS



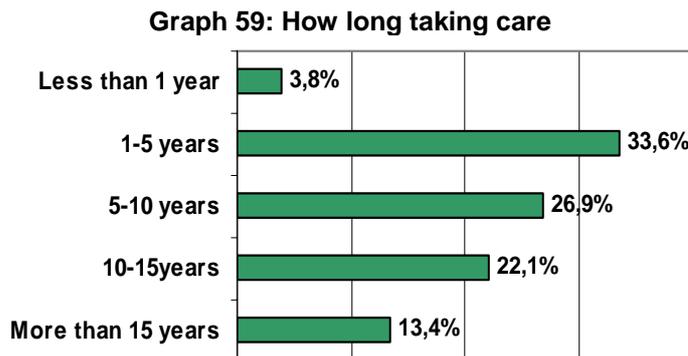
Moreover, those who represented by 12% and who said that they did leave the job for taking care of the person with MS, said that it was mostly because they preferred to be themselves who cared the patient (55.5%), as it can be seen in Graph 58. Another reason was that they could not afford to pay a professional for doing it (44.4%).

Graph 58: Yes - Reason

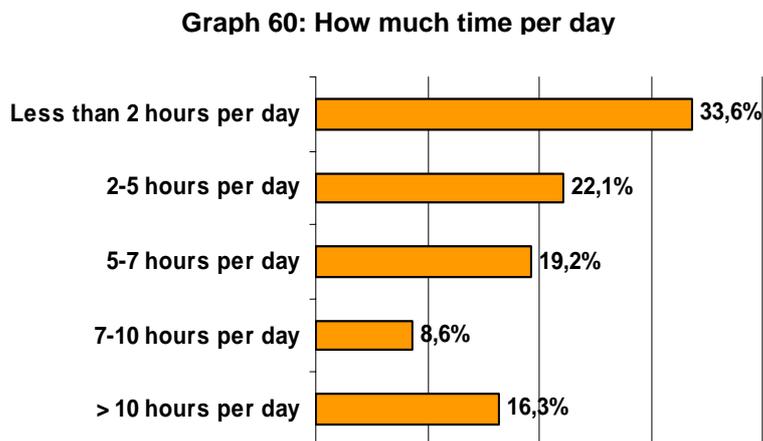


4.4. Data related care given and training level.

Concerning the care the participants give the patient with MS, most of them had been taking care of them for 1-5 years (33.6%), followed by those who had been doing it for 5-10 years (26.9%), and for 10-15 years (22.1%). These data are shown in Graph 59.



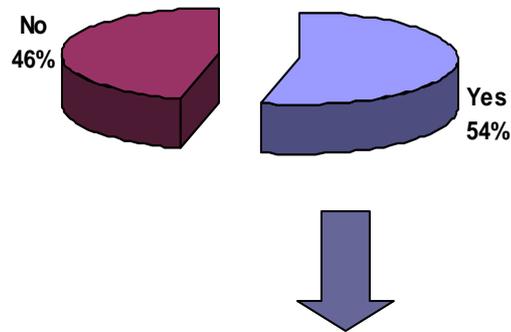
Moreover, when we asked how much time per day they devoted to the care of the patients, majority of them said they took care for less than 2 hours (33.6%). The other percentages can be seen in the Graph below.



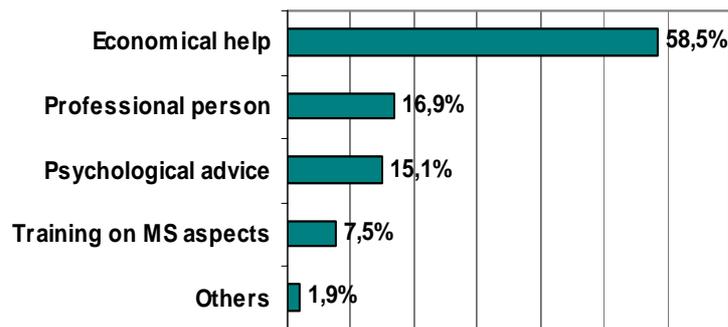
On the other side, most than half of the participants said that they did have some support for carrying out the care tasks with the person with MS, as shown in Graph 61. And when asked about the kind of support they received, 58.5% said that it was economical one; 16.9% said that they had a professional person who went to their home for helping them, 15.1% received

psychological advice and 7.5% got training on aspects related to MS. All this information can be seen in Graph 62.

Graph 61: Support for the care

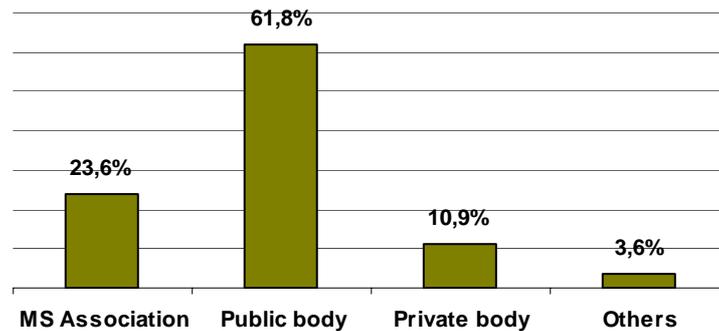


Graph 62: Kind of support



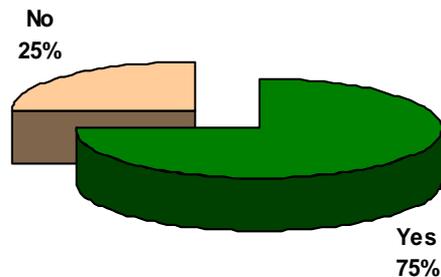
In most of the cases, the support came from public bodies (61.8%). At some extent, it came from MS associations (23.6%), private bodies (10.9%) and other sources (3.6%), mainly from family members or volunteer help, as it is shown in Graph 63.

Graph 63: Support coming from



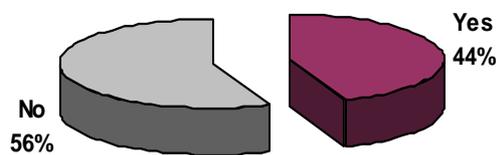
Next question was aimed at knowing whether the participant had specific knowledge about the MS patients' needs, and the results in Italy are quite different from the ones in the other countries, as here majority of them said they did have specific knowledge (75%).

Graph 64: Knowledge on MS patients' needs



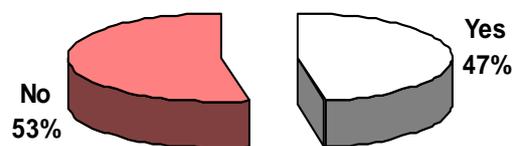
In spite of the results of the Graph 64, 44% of the participants said they found difficulties during the daily caring tasks, which is almost half of them, and 56% said they did not, as shown in Graph 65.

Graph 65: Find difficulties during care tasks



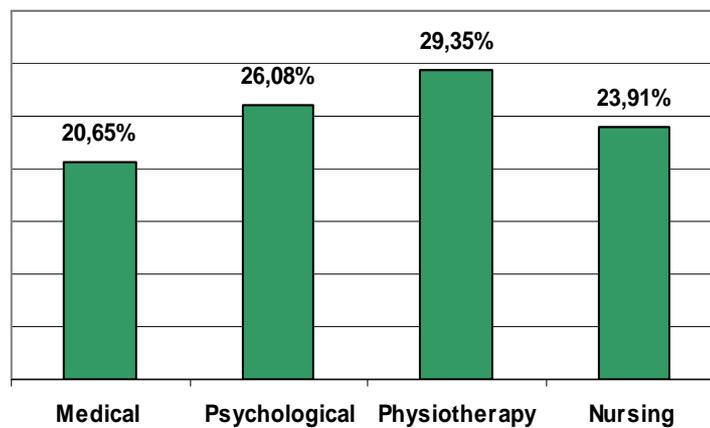
Moreover, next Graph shows also the knowledge needs the participants in Italy considered they had. Although they said (as seen in Graph 64) they had specific knowledge on MS patients' needs, 47% considered they needed to acquire knowledge for caring their relative with MS. 53% said they did not need to do it, as it can be see in Graph 66.

Graph 66: Need to acquire specific knowledge



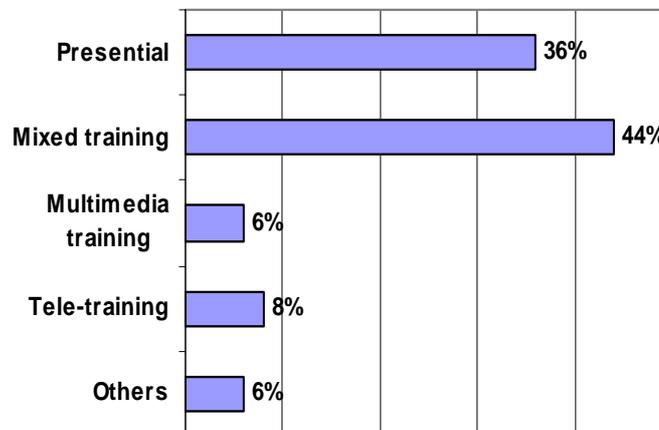
Regarding this 47% who needed specific knowledge, the field in which the need was most significant are shown in the Graph below: the first subject was the Physiotherapy (29.35%), the second one the Psychological aspects (26.08%), the third one the Nursery (23.91%) and finally the Medical aspects (20.65%). It must be pointed out that all the percentages were quite equalized among them, and that a lot of participants chose all the items, letting know that they felt a lack of knowledge in all the fields.

Graph 67: Yes - fields



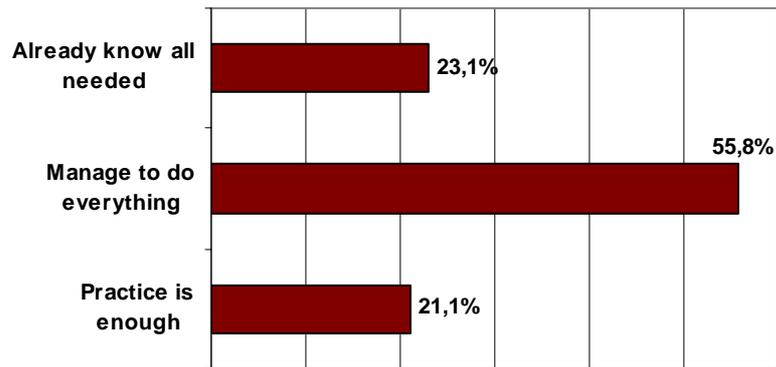
They were also asked about the most suitable method for receiving training in their opinion, and the results were the following: most of the would prefer the mixed training, that is some presential lessons and additional material for working at home.

Graph 68: Yes – most suitable method



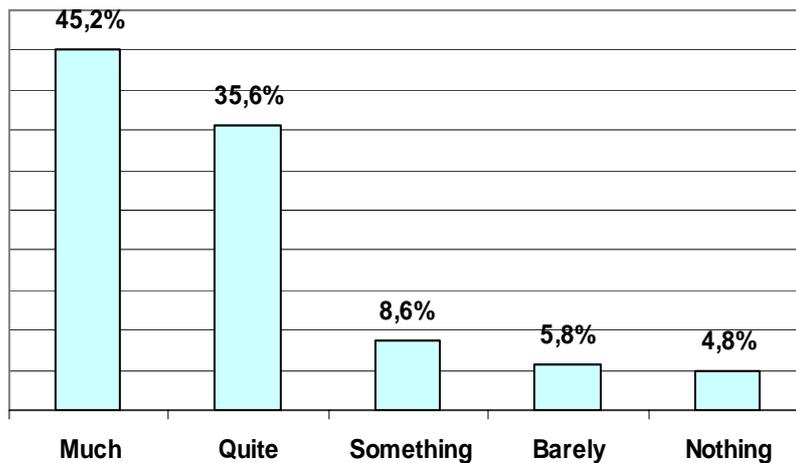
On the other hand, those who said they did not need to acquire specific knowledge (represented by 53% in Graph 66) told that the most significant reason was that they already managed to do everything (55.8%). Some of them said that it was because they already knew all they needed (23.1%), and finally some of them said that the day by day practice is enough, so they did not need to know anything else (21.1%). The results are shown in the Graph below.

Graph 69: No – Reasons



And finally, last question was about the extent the training in some of those fields would improve the quality of the caring tasks that the participants carried out. The results were very positive for the research, as almost half of the participants (45.2%) said it would improve it a lot, followed by those who said it would do it at a quite extent (35.6%). It is shown in Graph 70.

Graph 70: Training would improve the care quality



5. QUANTITATIVE RESEARCH IN SPAIN

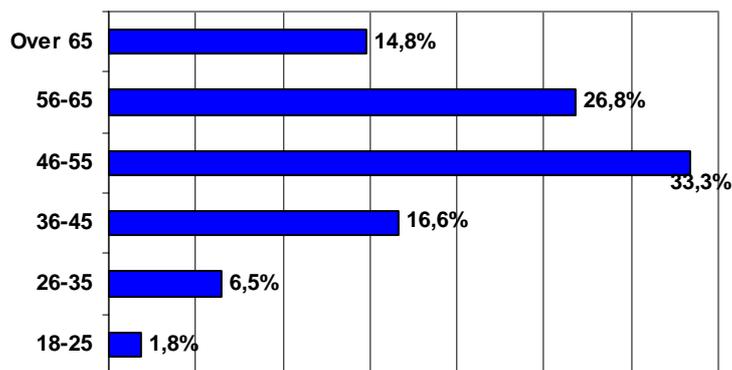
5.1. Personal data.

In Spain 109 questionnaires were carried out, distributed in several cities of the country, as each partner took the responsibility for it in its geographical area. Thus, the exact distribution of the questionnaires was as follows:

- Palma de Mallorca: 26 questionnaires;
- Mahón: 3 questionnaires;
- San Sebastián: 14 questionnaires;
- Bilbao: 23 questionnaires;
- Vitoria: 12 questionnaires;
- Madrid: 28 questionnaires.

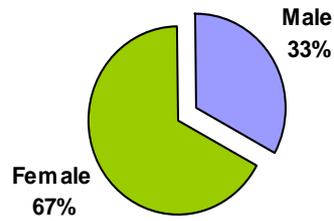
Concerning the personal profile of the participants in Spain, we can see the distribution of the age in the following Graph. IT must be notice that this the country with the oldest participants, as most of them were between 46 and 55 years old (33.3%), followed by those who were between 56 and 65 years (26.8%). In the other participant countries the average age was lower than in Spain.

Graph 71: Age



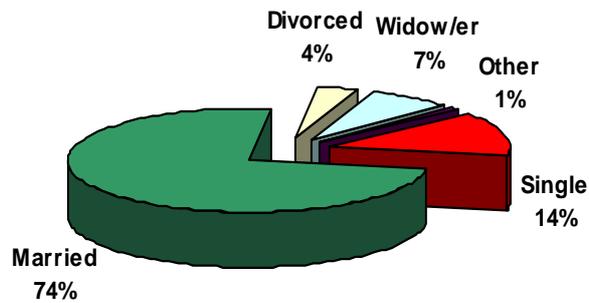
As far as the participants' gender is concerned, in Spain majority of them were women, as it can be see in the Graph below: 67% female and 33% male.

Graph 72: Gender



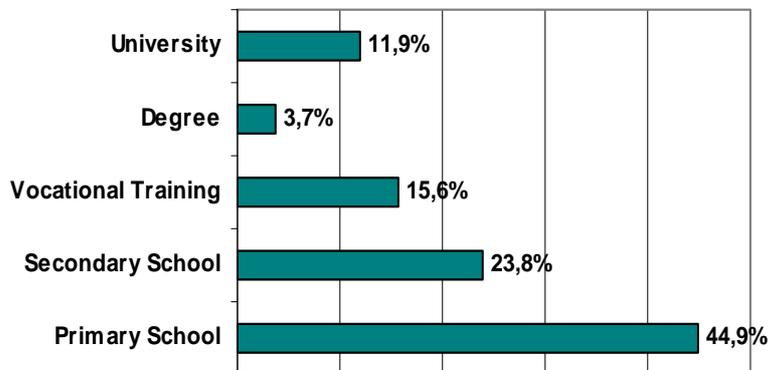
As well as in the other participating countries, majority of the Spanish interviewees were married (74%), as shown in Graph 73.

Graph 73: Marital status



Finally, regarding the educational level, 44.9% of them had only the Primary School degree, followed by those with the Secondary School degree (23.8%).

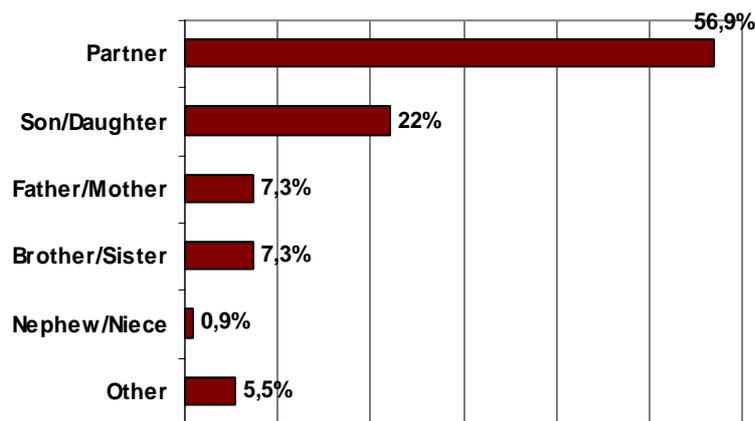
Graph 74: Educational level



5.2. Data regarding cared person with MS.

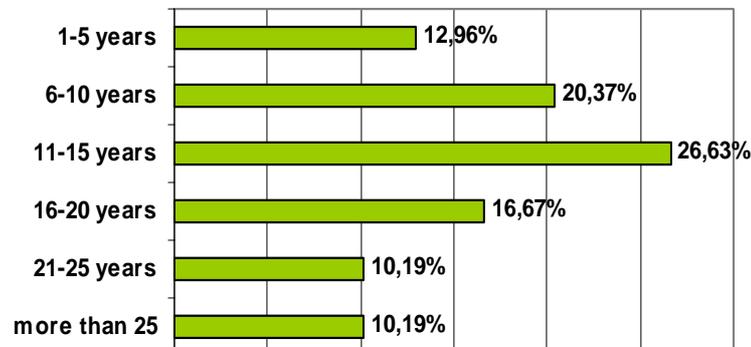
As well as in the other participating countries, the majority relationship linking the participants with their relative suffering MS was the partnership (56.9%), followed by those whose daughters or sons were the patients (22%). All results are shown in Graph 75. It must pointed out that, also in Spain, the item “others” (5.5%) include best friends.

Graph 75: Relationship with the person with MS



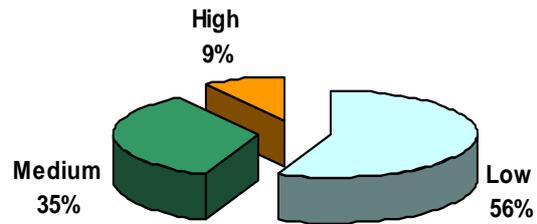
We can notice that in Spain the patients with MS had had the disease for longer than in the other countries: as it can be seen in the Graph below, 26.63% had had it for 11-15 years, 20.37% had had it for 6-10 years and 16.67% for 16-20 years. So, we can see that most of the patients had had the illness for quite a long time.

Graph 76: Years of disease



Concerning the autonomy level of the patients, it is also in Spain where the patients with MS had the lowest autonomy (56%), what means they need permanent assistance from persons or technical means. This percentage is followed by those who have a medium autonomy level (35%), and only 9% of the participants said that their relative with MS had a high autonomy level.

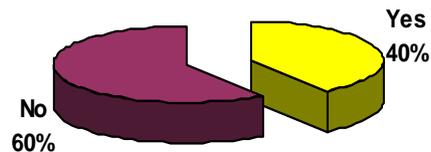
Graph 77: Autonomy level of person with MS



5.3. Social & labour data of the interviewees.

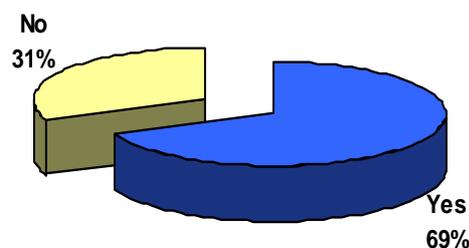
Most of the participants were not working when the survey was carried out (60%), as shown in Graph 78.

Graph 78: Currently working



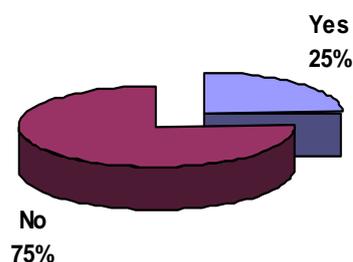
It is very significant that most of them were working before the MS diagnosis of their relative (69%) as it can be seen in Graph 79. So we can notice the big difference between those who were working before the diagnosis (69%) and those who were working when the survey was carried out (40%) shown in Graph 78. A logic deduction is that 29% of them left the work in that period, so influenced somehow by the MS diagnosis of the relative:

Graph 79: Working before the diagnosis



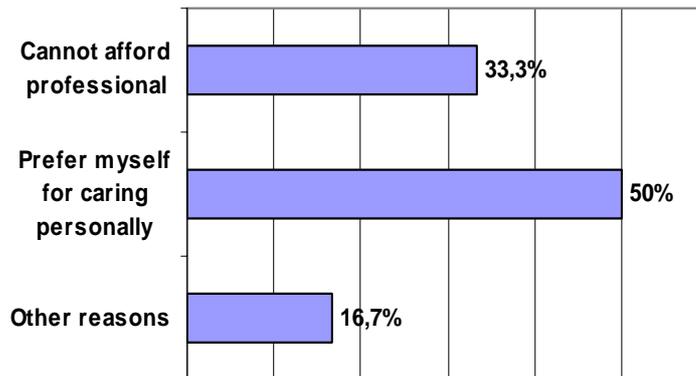
Moreover, we asked those who said they were actually working before the diagnosis whether they left the job for taking care of the relative, and 75% said they did not, 25% said they did, as shown in Graph 80.

Graph 80: Left work for caring person with MS



The reasons that this 25% gave are gathered in Graph 81 and were the following: half of them preferred be themselves who took care of the patient personally, 33.3% admitted they could not afford to pay for professional help and 16.7% said the reasons were others.

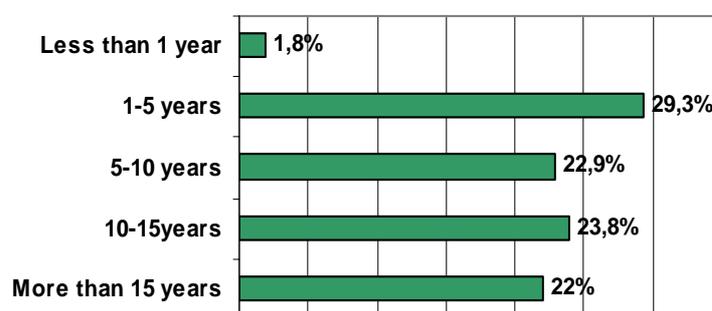
Graph 81: Yes - Reasons



5.4. Data related care given and training level.

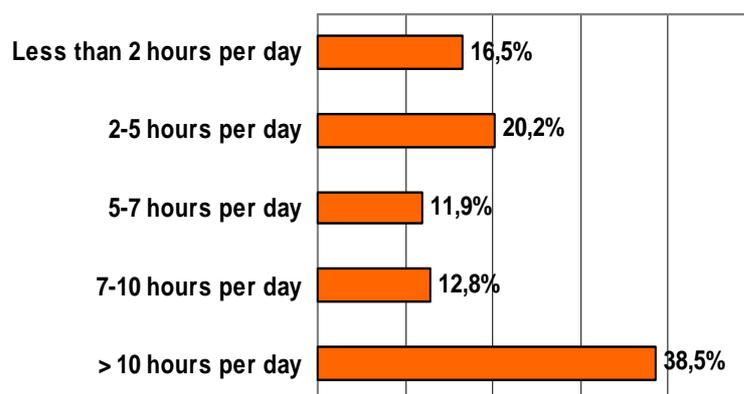
Concerning the time the participants had been taking care of their relative with MS, as we can see in Graph 82, majority of them had done it for 1-5 years, but this percentage was closely followed by those who had been taking care for 10-15 years (23.8%), for 5-10 years (22.9%) and more than 15 years (22%). It must be noticed that only 1.8% had been taking care of the relative for less than 1 year. The results are quite different from the ones in the other countries.

Graph 82: How long taking care



Directly linked with the autonomy level, whose results have been analysed in Graph 77, we can see the time the participants devote to the care of their relatives in the Graph below. Majority of them carried out caring tasks more than 10 hours per day (38.5%), percentage that was no so high in the other participating countries.

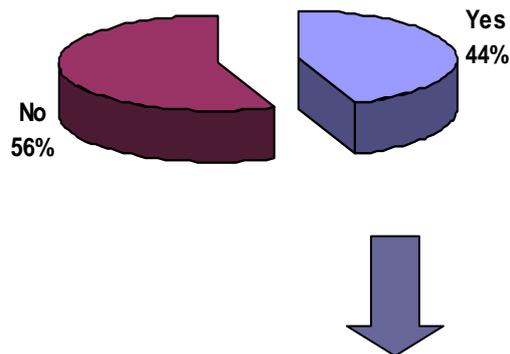
Graph 83: How much time per day



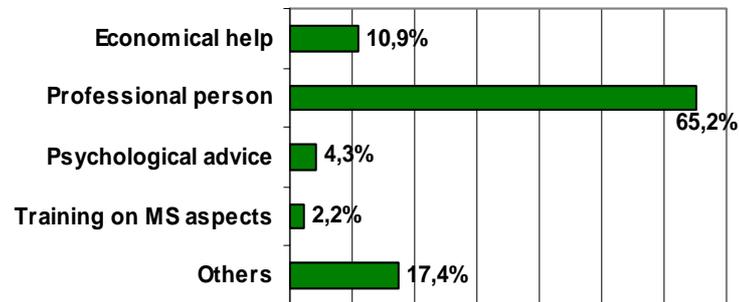
Moreover, 56% of the participants said they did not receive any support for the care tasks, and 44% said they did, as it is shown in Graph 84. When asked the latter group what kind of

support they were receiving, the great majority said that a professional person helped them in the care tasks (65.2%), as it can be seen in Graph 85. In this Graph, the percentage of “others” was also significant (17.4%), including the help coming from the family members, friends or technical helps.

Graph 84: Support for the care

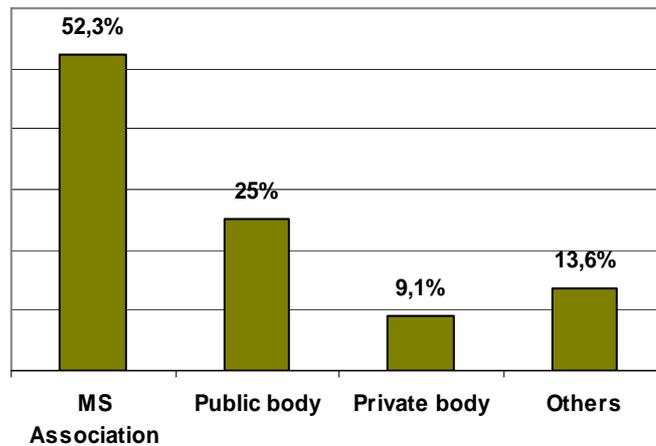


Graph 85: Kind of support



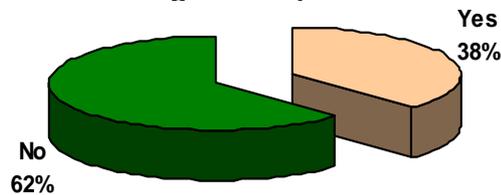
They were also asked where this support came from, and the answers can be seen in Graph 86: most of them said that it came from the MS associations (52.3%); some of them received it from public bodies (25%) and private bodies (9.1%). The option “others” (13.6%) included family and friends’ support too.

Graph 86: Support coming from



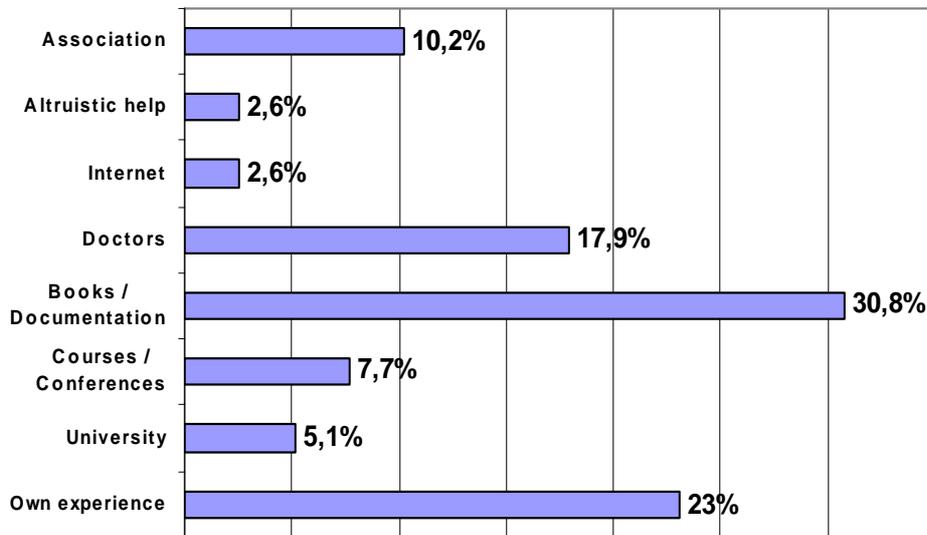
Next, the participants were inquired about the knowledge and training background they had from the care tasks. As first question, they were asked whether they had any specific knowledge about the need of the patients with MS, and 62% of them said they did not, as it can be seen in Graph 87.

Graph 87: Knowledge on MS patients' needs



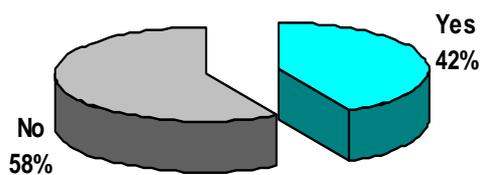
The 38% who said they did have knowledge on this subject, said that they had acquired it mostly through books and different sources of documentation (30.8%), followed by those who thought they had acquired that knowledge through the own experience and the day-by-day practice (23%). All the percentages are gathered in Graph 88.

Graph 88: Where and how acquired knowledge

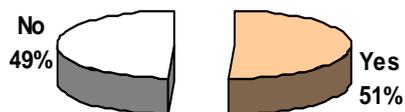


Concerning the difficulties they may find during the caring tasks, most of them (58%) said they did not face difficulties (shown in Graph 89), but when we asked them whether they thought they needed to acquire specific knowledge for the care, most of them answered affirmatively (51%), as can be seen in Graph 90.

Graph 89: Find difficulties during care tasks

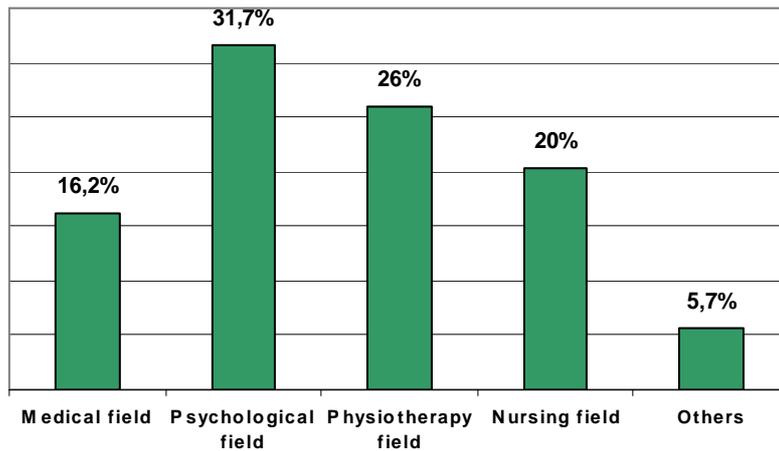


Graph 90: Need to acquire specific knowledge



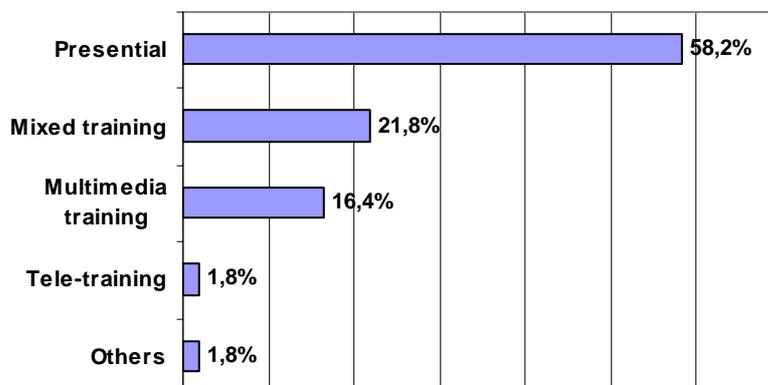
This percentage that answered positively (51%) said that the fields in which their needs were most significant were the ones shown below. Firstly, the psychological aspects (31.7%), secondly, physiotherapy field (26%), thirdly, nursery (20%) and the last one the medical field (16.2%). It must be pointed out that the item “others” (5.7%) was mainly including the transferences as the participants specified.

Graph 91: Yes - Fields



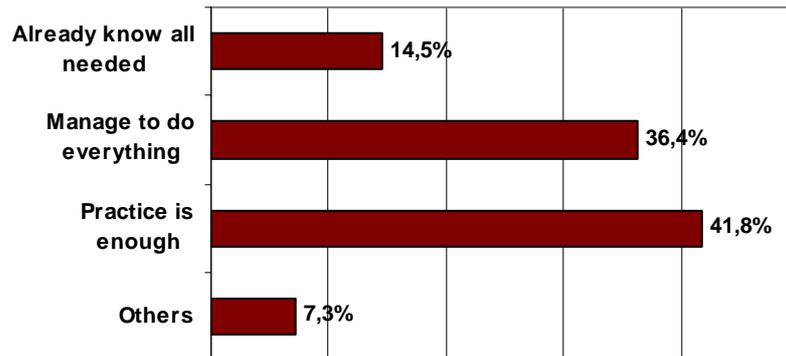
Moreover, they were asked about the most suitable methods for receiving training in the fields needed, and most of them said that the presential method was the best one (58.2%), followed by the mixed training (21.8%), which means a combination between presential lessons and other materials for being used at home or in the free time. The multimedia training was chosen by 16.4% of the interviewees.

Graph 92: Yes – Most suitable method



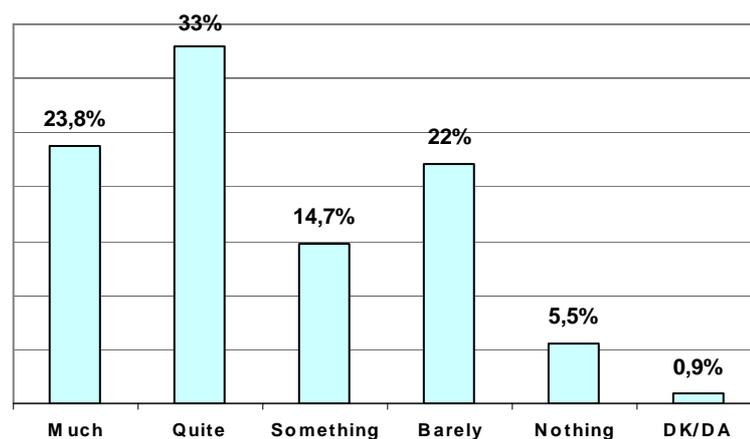
Those who thought they did not need to acquire any knowledge for the care tasks, said that the most significant reason was that the practice is enough for that and so they did not need any training (41.8%). Moreover, 36.4% said they already managed to do everything so they did not need additional training, and 14.5% said they did know all they needed.

Graph 93: No – Reason



Last question was about to what extent the training in some fields would improve the quality of the caring tasks they usually carried out, and the answers were the following: most of them said that it would quite improve it (33%), followed by those who said it would improve it a lot (23.8%).

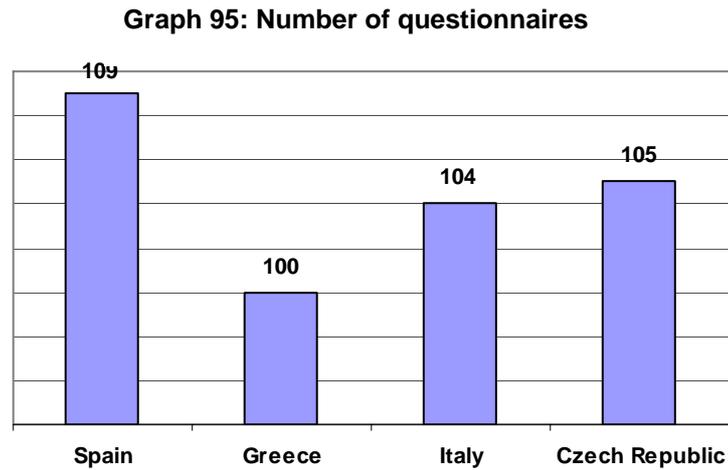
Graph 94: Training would improve the care quality



6. GLOBAL ANALYSIS

As far as a joint analysis is concerned, we will point out some conclusions at transnational level.

First of all, it must be mentioned that the minimum number of questionnaires to carry out was 100 in each country. On this basis, the number of questionnaires carried out was the one shown in the Graph below.

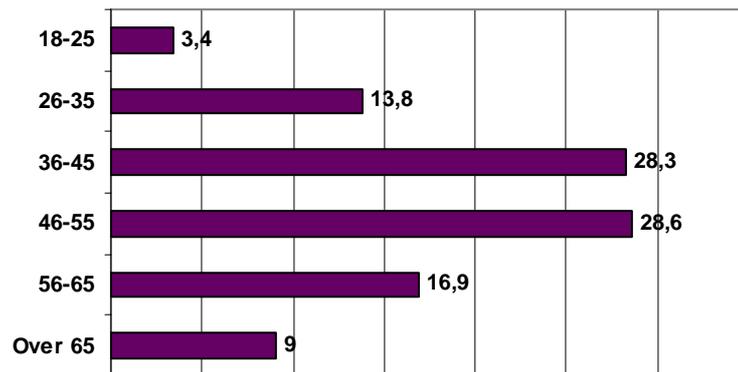


We will see below the whole results for each section of the research.

6.1. Personal data.

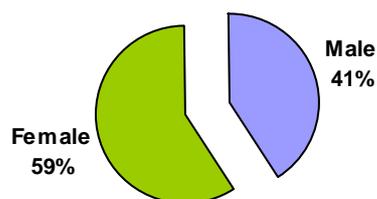
Concerning the age of all the participants, majority of them were between 36 and 55 years old, in all 56,9%, divided into two similar groups: 28,3% between 36 and 45 years old, and 28,6% between 46 and 55 years old. The other percentages can be seen in the Graph below.

Graph 96: Age (%)

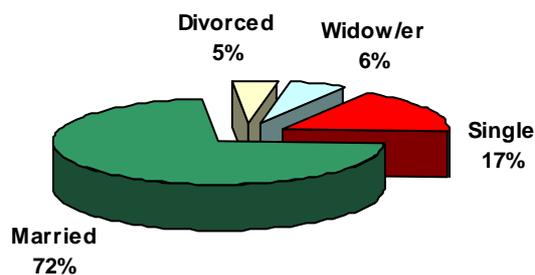


As far as the gender of the participants is concerned, majority of them were women (59%); moreover, as it can be seen in Graph 98, the great majority of the participants were married (72%).

Graph 97: Gender

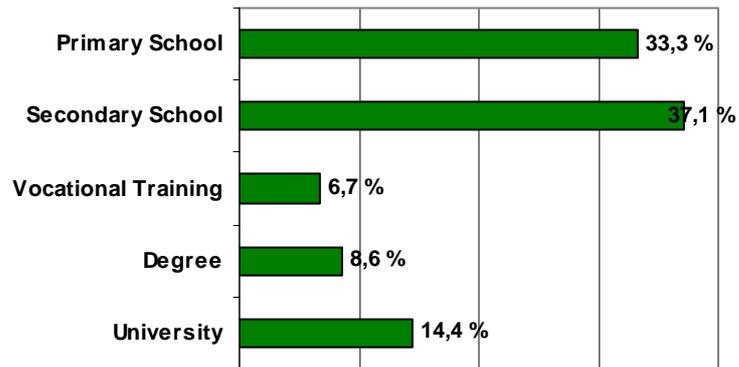


Graph 98: Marital status



Regarding the educational level of the participants, as it can be seen in the Graph, and according to the tender shown in the national results, majority of them had the Secondary School degree (37,1%), closely followed by those with the Primary School degree (33,3%).

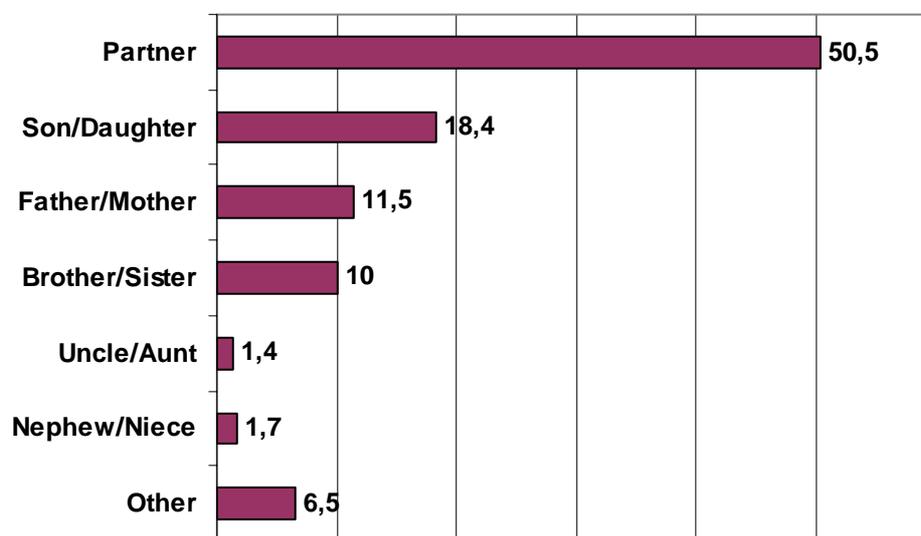
Graph 99: Educational level



6.2. Data regarding cared person with MS.

Concerning the relationship of the participants in the research with the person with MS they were taking care of, the global results show us that half of the participants had the partner suffering MS, both married and not (50,5%), and it was followed by those who took care of their son / daughter with MS (18,4%), and other percentages shown in the Graph below. It is interesting to mention that the item “others” included mostly those who took care of their best friend, linked by a very close relationship, and in some of the cases, the brother or sister in law.

Graph 100: Relationship with the person with MS (%)

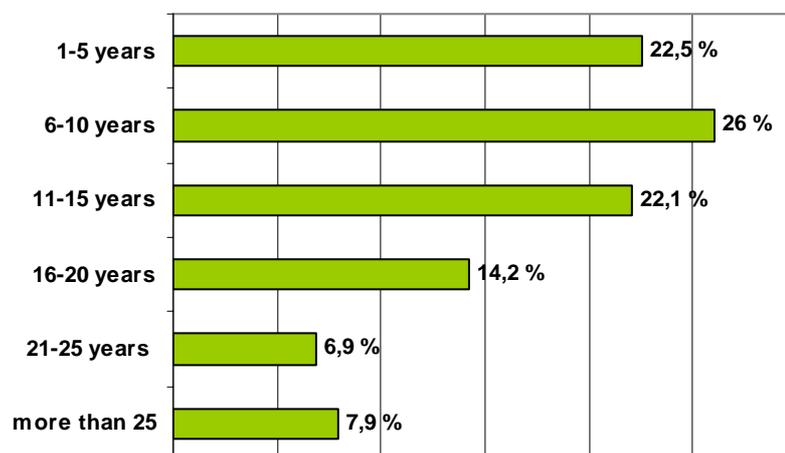


Next question dealt with the antiquity of the disease of the persons suffering MS cared by the participants since the diagnosis, directly linked with the next one, asking them about the autonomy level of the patient. Results of both questions are shown in Graphs 101 and 102, respectively.

Most of the participants' cared persons had had the disease for 6-10 years (26%), but this group was followed by those who had had it only for 1-5 years (22,5%) and by those who had had MS for 11-15 years (22,1%). In general, we can state that majority of participants were taking

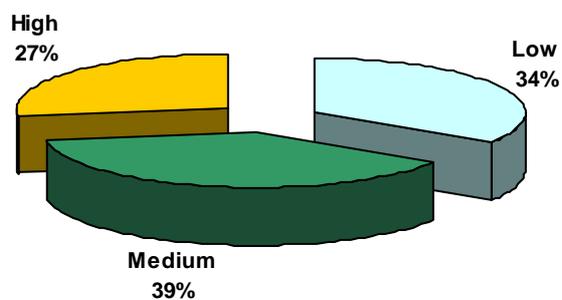
care of people whose diagnosis had been quite recent: 70,6% had been suffering MS for 1-15 years.

Graph 101: Years of disease of person with MS



As a consequence, the autonomy level of the patients with MS was mostly medium (39%).

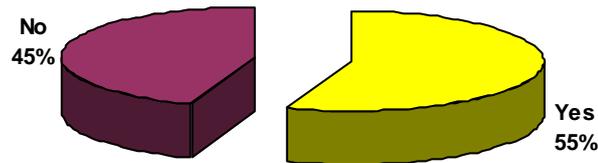
Graph 102: Autonomy level of person with MS



6.3. Social &labour data of the interviewees.

Concerning the labour situation of the participants, the global results show us that majority of them were working (55%).

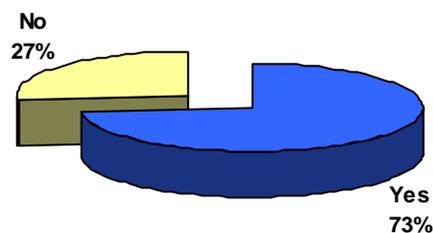
Graph 103: Currently working



It must be mentioned that in all the countries where the research was carried out the majority group was not working in that moment (60%) unlike Czech Republic, Greece and Italy, where majority of them were working.

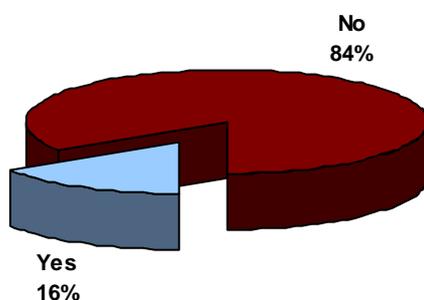
In any case, there is a big difference between those who were working before the diagnosis and those who were working when the research was carried out. As it can be seen in the Graph 104, 73% of the participants were working before their relative had the diagnosis of MS, but after some time, only 55% were still working (result of the Graph 103).

Graph 104: Working before the diagnosis



This is directly related to the next question, as those who answered affirmatively the question above (Graph 104), were also asked whether they left the job due to the necessity of taking care of the relative with MS, and the global result shows us that majority of them denied it (84%). Although the percentage of those who did it is quite low (16%), we must mention that the most common reason was that they could not afford a professional going to their home for helping them, and also those who said that they preferred to be themselves who took care of their relative.

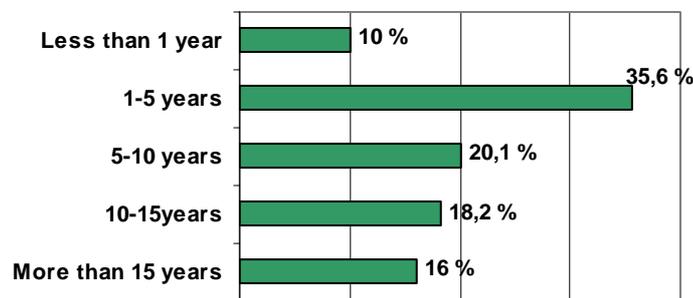
Graph 105: Left work for caring person with MS



6.4. Data related care given and training level.

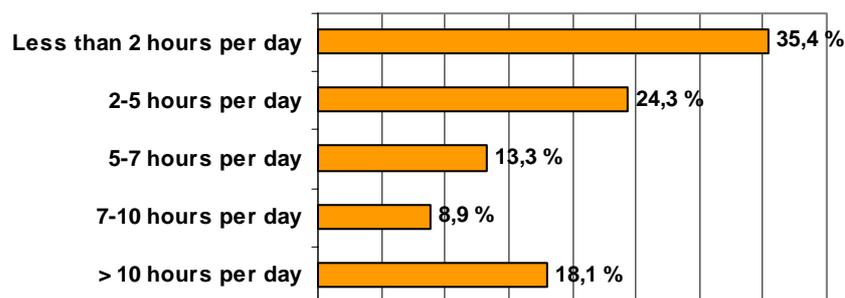
Concerning the time the participants had been taking care of their relative with MS, as we can see in Graph 106, majority of all the participants them had done it for 1-5 years (35,6%), but the other percentages were very close among themselves: care for 5-10 years 20,1%; care for 10-15 years 18,2%; more than 15 years 16%; and, finally, only 10% of them had been taking care for less than 1 year.

Graph 106: How long taking care



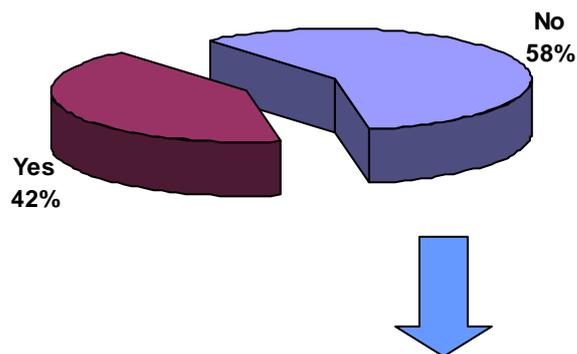
Moreover, in general, the participants took care for the relative with MS not more than 2 hours per day (35,4%), what is followed by those who did it for 2-5 hours per day (24,3%) and those who devoted more than 10 hours per day to the patient (18,1%).

Graph 107: How much time per day

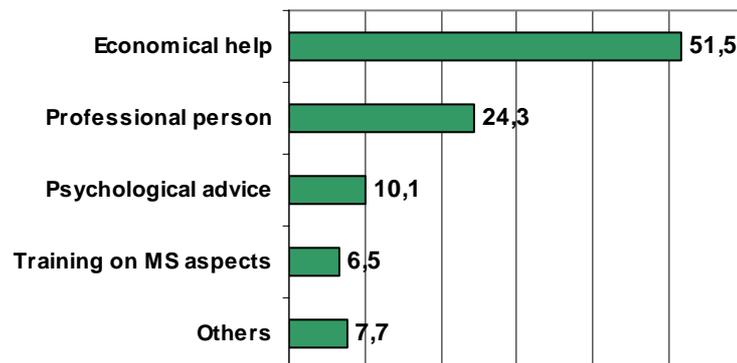


It is very interesting to see that more than half of the relatives said that they did not have any kind of support for taking care of the person with MS, more specifically 58% of them, as shown in the Graph below.

Graph 108: Support for the care



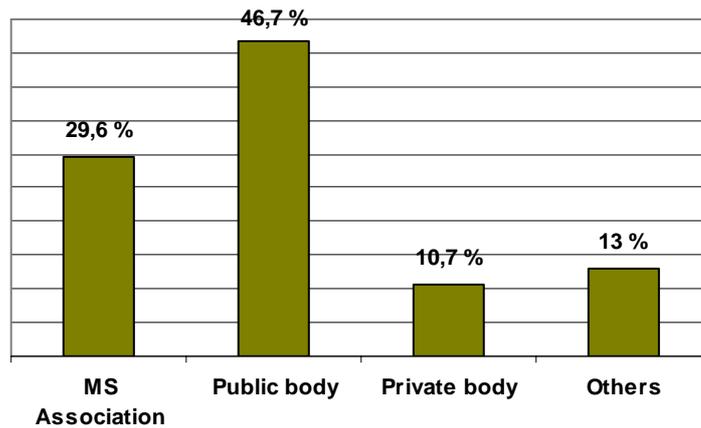
Graph 109: Kind of support (%)



Those who had support (42% of the whole participants), specified that it was mostly economical support, as it can be seen in Graph 109, and secondly it was the help of a professional person coming home (24,3%). Moreover, those who said they received other kind of support were mostly referring to family members who helped them.

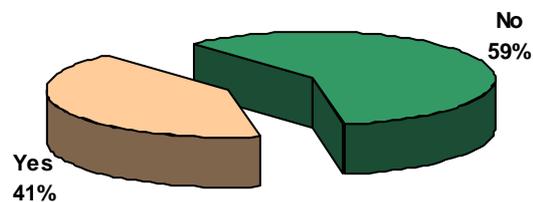
As far as the origin of the support is concerned, almost half of the support received in all the countries (46,7%) came from public bodies, followed by a quite high percentage of people receiving support from MS associations (29,6%). The item “others” was referring to family members or individual volunteers (13%).

Graph 110: Support coming from...

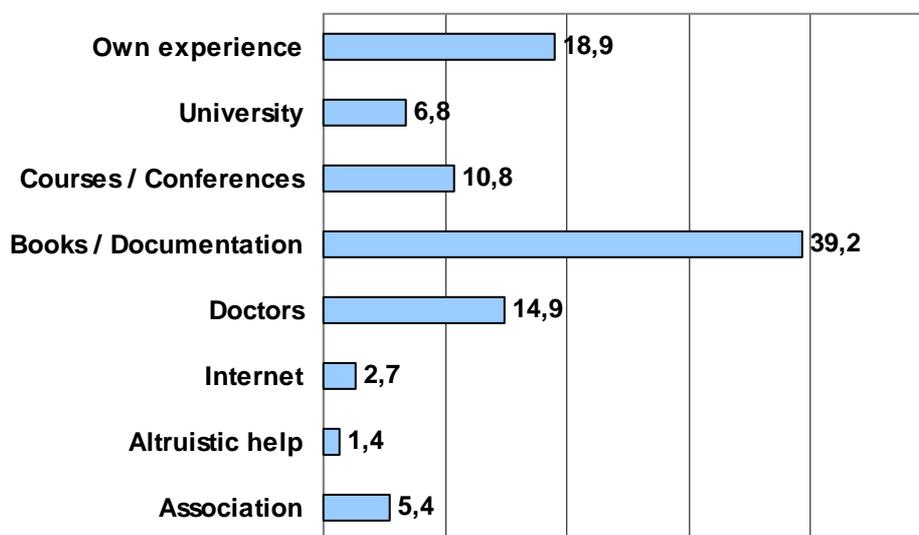


Most of the participants said that they did not have any specific knowledge on MS patients' needs (59%), and 41% said they had, as it is shown in Graph 111. The latter group acquired this knowledge mainly through reading books and documentation dealing with the disease (39,2%), but there were also other means, which can be seen in Graph 112.

Graph 111: Specific knowledge on MS patients' needs

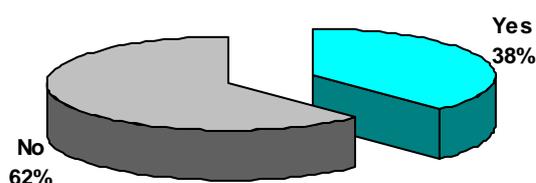


Graph 112: Where and how acquired knowledge (%)

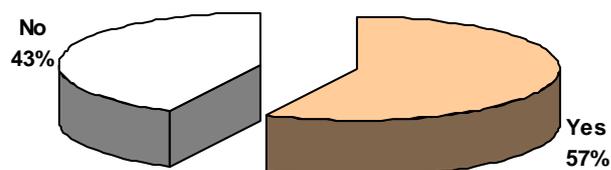


In all, minority of the participants said that they found difficulties in the daily tasks (38%), as it is shown in the Graph below. But when we asked them whether they thought they need to acquire specific knowledge for taking care of the person with MS, majority of them answered affirmatively (57%), as it can be seen in Graph 114.

Graph 113: Find difficulties in daily tasks

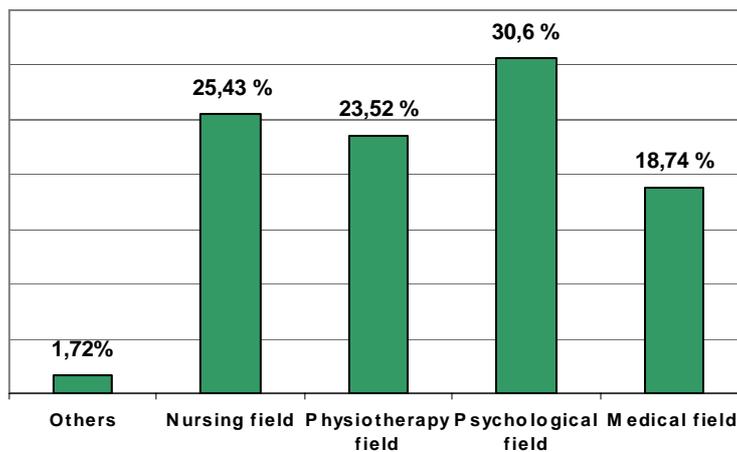


Graph 114: Need to acquire specific knowledge



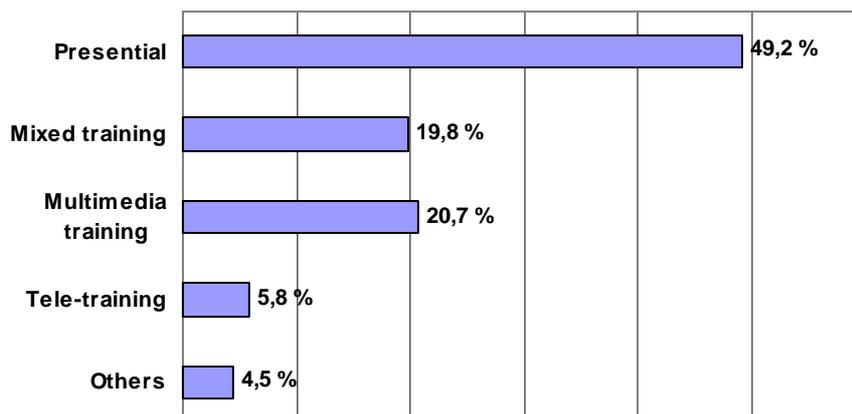
The fields in which the latter 57% thought they needed to acquire knowledge were as follows: firstly, they felt the biggest lack in the psychological field (30,6%); secondly, in nursing field (25,43%); then, physiotherapy field (23,52%); and finally, medical field (18,74%). It must be mentioned that, there was also a percentage of people who added other fields in which they felt a lack of training (1,72%), meaning mostly transferences of the ill person.

Graph 115: Yes - Fields



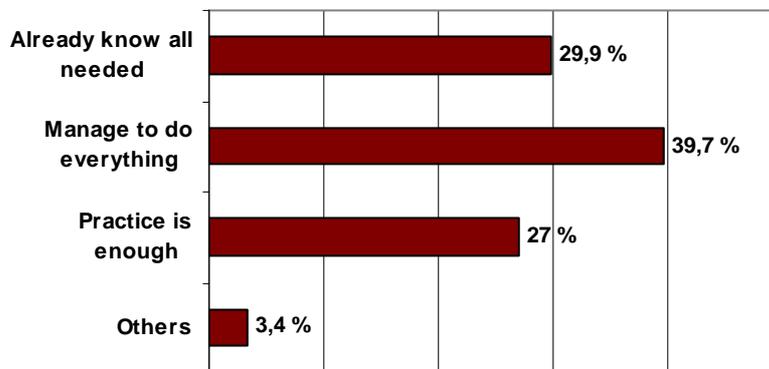
Globally, for this group of people, the most suitable method for acquiring knowledge would be the presential one, in a training centre (49,2%), followed by the multimedia training which is training based on a CD ROM (20,7%) and the mixed training, which combines a CD ROM and lessons in a training centre (19,8%). It must be mentioned that the item “others” (4,5%) included several methods such as the attendance to conferences or the self-training through books, documentation or Internet. All the results can be seen in Graph 116.

Graph 116: Yes - Most suitable method



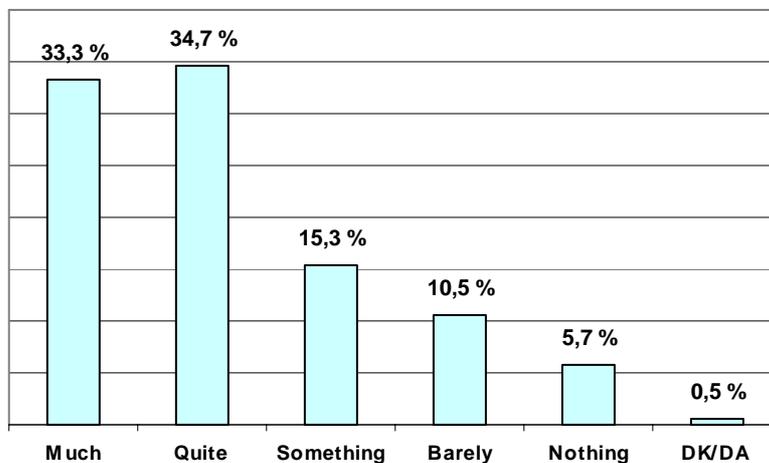
Those who answered negatively in the question of the Graph 114 (43%), were asked about the reasons: most of them said that it was because they managed to do everything quite well (39,7%); the next percentage belonged to those who said they already knew all they needed (29,9%); the relatives who said that the practice was enough represented 27%. Finally, there was a group of people who said that the reason was “other” (3,4%), mainly because they did not have time for receiving training, mostly in the Spanish research.

Graph 117: No - Reason



The last question of the questionnaire can be considered a final summary of the information requested, since participants were asked to what extent training in the fields above would improve the quality of caring tasks for the person with MS. The answers were as it is shown in the Graph below:

Graph 118: Training would improve the care quality



Majority of them gave a positive answer, as 34,7% said it would improve the care tasks quite and 33,3% said it would do much. So, in all 68% thought that training in some specific fields would be very useful. It must be mentioned that the country where the positive percentage was the highest one was Greece, followed by Italy. This is one of the most significant results from our research for the next stage of the project, which will be the elaboration of the training tool.

C. QUALITATIVE RESEARCH

1. INTRODUCTION

According to the process of the research in the framework of the Work Package 2 of QUALIFIED CARE project, a Qualitative research was carried out in all the participant countries, including the execution of Interviews and Focus Groups among collectives that provided us with useful information for the further development of the training tool. At the same time we promoted the exchange of information among the people suffering MS, their relatives and the professionals working with them.

The aim of the application of a Qualitative Methodology was to meet the need of observing the reality regarding the real training necessities of the relatives who take care of patients with MS, and the environment of this topic from a professional approach. That is why we proposed to elaborate a research methodology based on the following techniques: in-depth Interviews and Focus Groups.

As far as the **in-depth interviews** were concerned, they consisted of a technique of obtaining information through a specific type of face to face conversation. The interviewer had a list of the main questions to be asked, and the guidelines of the interviews were the same for all the countries, intending to ensure that the same general information areas were collected from each interviewee. Professional people who worked with people with MS were interviewed, including different profiles: labour guiders, counsellors, doctors, psychologists, physiotherapists, nurses, counsellors, etc. Each country had to carry out 6 interviews at least, fulfilling most profiles as possible.

Concerning the **Focus Groups**, they created a process of sharing and comparing among the participants. Our technique was based on the method of the Focus Group, but with less people than the usual way: we involved between five to seven people and, although conversation was structured around a discussion document, it allowed spontaneous and deep seated feelings on a subject to emerge naturally. They lasted from around one and a half to two hours, and they were run by an appropriate chairman. The moderator's task was to facilitate the discussion, encouraging all respondents to contribute with their thoughts, feelings and ideas. The chairman was provided with guidelines, which was semi-structured and contained the most important questions for the participants.

Taking into account that some participant countries had more than one partner entity, such as Greece and Spain, they carried out two Focus Groups: one with people suffering MS and the other one with

relatives of people with MS. The other partners, that is Italy and Czech Republic, carried out only one Focus Group, among relatives of people with MS. The Focus Groups were recorded, in order to make easier the gathering of all the information. The conclusions obtained by each partner have been gathered in this document exactly as were elaborated by them.

2. QUALITATIVE RESEARCH IN CZECH REPUBLIC

2.1. Interviews and Focus groups.

Here we gather the most significant conclusions obtained from both the interviews with professionals and the relatives of people suffering MS.

According to the requirements established by the partnership of the project for carrying out the qualitative research, the participants in the **interviews** carried out in Czech Republic fit the following professional profiles:

- Doctor, after graduating from the medical school in 1993, she started to work in the district hospital at the neurological ward, where she was engaged in caring of patients at the acute ward block with different neurological diseases. Since 2001, she works in the St. Joseph Home. It is the only ward block institution in the Czech Republic specialized in the complex treatment of patients with multiple sclerosis. She has worked there from the very beginning. Since then she specializes in the treatment of multiple sclerosis, she study the professional literature, participates in different seminars, visit similar institutions in Germany and Great Britain, and gains experiences through a development of persistent medical treatment procedures.

- Psychologist, she graduated in 1988 from the Faculty of Philosophy and Arts of the Charles University in Prague in the department of psychology, already during the preparation of her thesis, she specialized in psychotherapy and clinical psychology. After studies, she worked in the psychiatric hospital in Prague – Bohnice and since 2000 she is employed at the neurological ward, which comes under General faculty hospital in Prague. A MS centre is also part of the ward. She occupies herself with psychotherapy and psycho diagnostics and about 60 percent of her clients are patients with multiple sclerosis.

- Nurse, she finished the 4-years secondary medical school, and then followed up with 2-years study focused on nursing care of adults in surgery. Then she worked 2 years at the internal ward, then 6 years in surgery and then 1,5 years in the home care. After the maternity leave, she started to work in the St. Joseph home, where she works until now.

- Physiotherapist, after finishing a medical high vocational school with focus on physiotherapy, she started to work in the St. Joseph Home, where she works as a physiotherapist. She has been interested in care of patients with MS already during her studies, when she was here in articles and she also wrote a thesis on the treatment of MS. She supplements her knowledge with short courses, e.g. now courses in lymphodrainage.

- Physiotherapist, she finished her studies of physiotherapy at the Faculty of Physical Education and Sport of the Charles University in Prague, in 2004 she finished postgraduate studies in neurosciences – the importance of physiotherapy in the treatment of multiple sclerosis. She is a founder of generally beneficial company CEROS, whose goal is to build a centre – hierarchized system of institutions, which would ensure a timely, persistent, specific and complex care for patients with multiple sclerosis in the whole Czech Republic. Within the scope of the project Multiple sclerosis in the net and due to cooperation with several institutions, CEROS can already now offer an expanding network of special services to MS patients: physiotherapy, ergo therapy, cognitive rehabilitation, urorehabilitation, logaedics, psychotherapy, dance therapy, music therapy, art therapy, social and legal consultancy, hippo therapy, recreational activities, workshops, seminars.

- Male nurse, after about 10 years as an electrician, he started to work as a male nurse in Germany, after return to the Czech Republic, he kept working as a male nurse. He worked two years in the Charity, seven years in an old people's home and since 2001 he has been working in the St. Joseph Home. He did not finished his nursing education, he acquired knowledge especially through practice, according to him the most important part of this job is a relation to the patients and it cannot be taught in any school.

- Nurse, after finishing a grammar school she completed 2-years nurse course and then she worked almost 40 years as a nurse in the hospital, gradually at the neurological, dermatological and internal ward, then in the old people's home and now she has been working in the St. Joseph Home already for two years. She has acquired a lot of experiences during her lifelong career, which she now uses in the care of patients with MS.

-Ergo therapist, after finishing her studies at the secondary medical school, she finished a bachelor study at the 1st Medical Faculty at the Charles University in Prague, specialization in ergo therapy. Immediately after finishing studies, she started working at the faculty. Patients with MS comprise only smaller part of her clients.

Moreover, the persons who participated in the **Focus Groups** carried out in the Czech Republic were all of the close relatives of people with MS, as established by the methodology for this research.

As general conclusion obtained from the interviews and Focus Groups with both the professionals and the relatives, it turns out that all of them consider the creation of the multimedia training tool for the relatives of the patients to be useful, they do not doubt about its importance in any way and they agree to a high degree, what such tool should include. The only difference in opinions is that according to some of the relatives, the tool should be divided to 2 parts (e.g. 2 CD-ROMs) according to the extent of disability. They believe that for the patients with MS in the initial stage, when there are no apparent serious symptoms, it would be a too drastic vision of the further phases of the disease that may (but may not) set in. The relatives believe that this recognition could bring them down and put them off from the active putting up with the reality. So the information should be provided successively, according to the extent of the disablement.

As far as the content of the CD ROM is concerned, both groups agree that recently there is relatively enough information about the MS in the Czech Republic. Though, they think that the information about this disease should not be missing on the CD-ROM and it should include the current state of knowledge. Although much information can be found in the form of several publications or websites, the users will surely appreciate, if it will be in a well-arranged way and in one place – on the CD-ROM.

Concerning the information about the disease, it can start by a description of its history, how the approach to it and its treatment was changing. Further there should be an overview of occurrence of disease. In this part, the text should clearly answer to these questions:

- what are the places of occurrence of MS
- who is likely to get ill with MS

- in what age will MS most likely come
- what is the cause of MS

To be able to answer these questions means to study the environment and genetic factors.

Separate chapter with graphic representations should answer the question how MS starts, and also the question why MS requires a bit of theory.

Symptoms of MS are various and in the beginning they may seem so insignificant for the patients, that they do not realize anything or they make no connection between them and MS. Therefore this part should describe well the following symptoms:

- sensitivity dysfunction (mostly with unpleasant numbness - parasthesia),
- mobility dysfunction,
- dysfunction of brain nerves, appearing by double seeing,
- little brain dysfunction, appearing by limb shaking,
- balance or coordination problems,
- fatigue ,
- sphincter difficulties – disorder of evacuation of urine and stool,
- sexual dysfunction,
- emotional problems.

For both patient and his/her closest relatives and friends, the most important answer is at the question how MS normally proceeds. Here it would be necessary to explain the terms like attack, remission, regression. It is also necessary to stress that MS is a very unpredictable disease. It is surely useful to read about the possible process of the disease, but one has to realize that this does not mean that it will be also in this particular case and that the disease can have absolutely different process. The most important is, how soon it is diagnosed and how soon is it started to be treated.

A very important issue for each respondent is to cope with the disease psychically. This issue should have sufficient space on the CD-ROM. It concerns not only the patients themselves, but also their relatives. Shock is usually the first reaction to the diagnosis of MS – it is very natural,

automatic reaction and it cannot be required of the patient to take the situation „reasonably“. Then, a phase of refusal and denial often follows. The patient doubts the disease, he/she tries to behave as there were no problems, tries to forget the disease. In the next phases, there often appear feelings of anxiety, anger, impotence and depression. It is important to have a possibility to show their own feelings and fears, to get not only information, but also emotional and relation background at their closest relatives and friends, and also at their doctor and nursing staff.

After subsiding of the first reactions, a process of acceptation and acquiesce may follow – creation of the solution of the crisis. It means to seek a solution how to cope with all these changes – finding their own identity, space, where they live, role they play, society of people they meet and also what they can expect from the future. In this phase, the relatives can be a big support for the patient.

Process of coping with the MS diagnosis can have 3 approaches:

1. Denial:

- refusing to accept MS
- trying to live as the disease does not exist
- non-adapting to the changes
- accusing others from the problems

2. Over acceptance:

- total resignation to the disease
- overdone identifying with the disease
- using the disease as an alibi
- leaving social contacts

3. Balanced attitude:

- accepting the restrictions, but not resignation to the disease
- adapting to the new way of life, new roles at home and in the society
- trying to live fully and to be beneficial as much as is possible
- creating a new meaning and aim of life

Crisis does not need to be taken as a tragedy. In some cases it becomes even an opportunity to change, to rethink life priorities, and even to enrich and fulfill the meaning of life despite the barrier.

The relatives should not allow the patient to retreat within himself. They should know that lament and sadness are natural reactions to the disease. It takes only some time and in this period, there is a need for psychical support. However, sadness can change to depression, which is a very serious, but curable mental disease. Usually it is defined as a pathologic mood dysfunction, not equivalent to conditions.

Symptoms of depression are gloomy mood, reduction of energy and reduction of activity. Other symptoms of depression are:

- decline of ability to feel joy
- decline of interests
- decline of concentration and memory
- feelings of guilty and inferiority
- sad and pessimistic outlook of the future
- ideas of self-injury, suicide
- anxiety
- sleep dysfunction (sleeplessness, less often over sleepiness)
- food intake dysfunction
- physical symptoms (dizziness, feelings to vomit, long-lasting pains in different parts of body, difficult breathing, problems with swallowing)
- fatigue syndrome, restlessness.

Relatives should realize that depression as a syndrome of mental dysfunction cannot be managed by one's will, it makes no sense to tell the patients to cheer up and not to think about their problems. The only solution is a treatment at a specialist. Psychotherapy can help at mild forms of depression, in other cases giving antidepressives proved useful.

Psychotherapy come in useful not only in the treatment of mental dysfunction, but can also help very much in the process of coping with MS. It may be either in an individual, or in the group form. Sometimes there is still appearing a prejudice that use of psychotherapy is a proof of weakness, but there is no reason to be ashamed for that, on the contrary it is a prove of attempt to fight actively with the bad life situation and to deal with it.

A separate chapter should be the information about possible ways of treatment of MS. The problem is that there is no credible explanation for the fact that MS cause to some patients only minimal invalidity during 30 years, while it makes invalids from other patients just in several years. Though, current medicine has a lot of to offer to the patients. It concerns three areas:

- treatment of the acute attack
- restriction of the activity of the disease, it means reduction of number of the attacks
- treatment of the symptoms of the disease

Treatment of the acute attack lies today first of all in taking methylprednisolon. It is a corticoid and both patients and doctors are usually afraid of these drugs generally. Therefore it would be useful to explain their advantages and to warn of the danger of their possible negative effects, which need to be in mind. For example, patient treated with corticoids should not smoke. This combination increases predisposition of creation of excessive blood sedimentation rate and there is a risk of thrombosis. Even more serious is a combination of smoking and hormonal contraception for women. Corticoids may also cause osteoporosis, diabetes, gastric dysfunction and other problems.

Long-lasting treatment to influence a process of the disease use drugs of the first choice (interferon beta), second choice (intravenous immunoglobulin), third choice (Azathioprin) and other drugs.

Finally, there should be an explanation of the systematic treatment, which restricts the symptoms appearing with the attack. This includes spasticity, sphincter problems, balance problems, fatigue, depression and others.

Concerning rehabilitation, respondents agree on the importance of exercise, physical and mental training for the further process of MS. Not all patients have a possibility of professional advice on exercise, so this could be also a separate part of the CD-ROM in the opinion of the participants. Moreover, it is an activity, where the relatives of the people with MS can be very useful.

Text should include an explanation of how big physical activity is reasonable for the patient, how should he react on the fatigue, how can he recognize a good intensity of the exercise, which types of exercise should he choose, how many times a week and how long should he train etc.

Apart from general rules, common for all patients, it would be reasonable to divide exercise in several groups according to the extent of disablement, for example as follows:

1. Patients who have no mobility dysfunction. They can use all types of exercise for the following groups. Apart from that, the text should include recommendations concerning their own mobility activities.

2. Patients who can walk independently or with a tool. This category includes also patients walking on crutches. Exercises in this group are divided to stretching and loosening-up exercises, breathing exercises, exercise and weight training on upper and lower extremities, throat and trunk musculature. Then, exercises in a lying position on one's side, on the belly, on one's knees, sitting and standing follow.

3. Patients on the wheelchair moving by themselves or with help of another person. Patients placed in this group have often harder mobility dysfunction of some of their extremities. Therefore, it is important and necessary to do a passive exercise with motionless extremities. Another important thing is positioning. Passive exercise can be done in all positions.

Apart from that, it is possible to do an active exercise as for the group no. 2, if the patient is capable of that and it can be also supplemented with an exercise in sitting position and an exercise with a ball.

For the participants, mostly for the relatives, it is important to teach the relatives to treat with the patients correctly. It concerns for example:

- a. putting a bed pan under
- b. nappy or panty
- c. lifting to the sitting position
- d. rotation on their side
- e. rotation on the belly
- f. moving from the lying position on their side to the sitting position
- g. helping to get them on the wheelchair
- h. helping them to sit at the toilet
- i. helping them into the bath
- j. helping them to the ground
- k. lifting from the ground
- l. ride with a wheelchair
- m. moving from the car to the wheelchair

These actions could be demonstrated with a drawing with description, or with a video record. It is not easy to learn it, so an illustrative manual useful for both patients and their relatives.

4. Lying patients, depending on the help of another person. For these patients, the most important thing is correct positioning, passive exercise and good hygiene. The goal of these is to improve their breathing, to keep mobility of their joints and to keep or improve their physical condition.

5. Patients with ataxia. This group includes the patients with balance and coordination dysfunction and with shake. They should do the exercise on the floor to avoid possible falling.

6. Patients with urinary problems. The goal of the exercise for these patients is to strengthen the pelvis muscles, to promote the blood circulation of the lesser pelvis and adjustment of the regular evacuation. There is a big range of exercises for such patients.

People with MS are not supposed to do all types of exercise. The participants recommend that everyone should choose his/her own set of exercises, which suits him the best. However, then he should be conscientious and do the exercise regularly. Creation of such a set of exercises should be a result of cooperation with a physiotherapist. The role of the patients lies here in encouraging them and helping them with some of the exercises.

Neurorehabilitation brings new possibilities for the patients with MS. With its help and thanks to natural properties of the central nervous system, we are able to influence the control process. For example, in case the patient cannot move with his/her hand because of interrupted nerve connection. When we ensure an appropriate setting of the position of the body and if we stimulate the patient appropriately, we can produce the movement of the hand. This causes a connection of neurons in the brain area, which allow an easier making of the movement for the next time. It is necessary to realize, what caused the easier making of the movement and to try to make use of it in normal life. Only by repetition of the information, it is possible to influence positively control processes and movement stereotypes. In such way, it is possible to influence especially mobility dysfunctions (paralyze, escalated muscle tension, shake, sphincter problems etc.).

This exercise requires an introductory training by an instructed professional, but in the next phase it is also possible for the relatives to help the patient with the exercise. Illustration of possible exercises could be also part of the CD-ROM.

Dancetherapy effect lies in the movement with the music, which helps with making the movements, breath controlling and their own inspiration. From the preliminary scientific results, it follows that a regular exercise with music and meeting with people with similar problems has a positive effect on the psychical and physical life quality and stability and helps the patients to approach the results of common population.

It is one of the most effective forms of rehabilitation. Rehabilitation with the help of horse's movement, respectively his back, has three forms:

1. hippo therapy
2. medically-pedagogical riding
3. sport riding for the disabled

For the purposes of the CD-ROM, a description of the first two would be convenient.

Patient with MS is usually put off by this disease, someone loses job, and someone loses his /her partner, someone both. In most of cases, they retreat within themselves; then comes

depression and this will not improve the process of the disease. It is necessary to do something, inactivity doesn't solve anything. Art-therapy is a well-tried means for that. Art activities are one of the great ways to self-realization, to get a joy from creation, to self-recognition and sometimes also to overcome one's own, often only seeming bounds of possibilities.

During the disease, patients with MS need different tools. The range of them is quite big. It is probably not possible to create a database of all possible tools, but it would be very useful to create at least a functional description of each tool, when and how they may be used, what is needed to be taken into account, what should the patient prevent from.

For walking, and according to the extent of dysfunction and state of muscle strength, it is recommended to use sticks, crutches (French, Canadian, underarm, forearm), and baby walkers. Supplements of these tools are nonskid attachments on the stick, clip to stick. Sometimes it is necessary to use orthopedic shoes, reinforcement of the joint, peroneal tape, splint, and bandage.

Mechanical wheelchair is for people who still have strength in the arms. For people with reduced strength in the arms, an electric wheelchair is indicated. For the ride in the interior, it is better to have a wheelchair with bigger wheels at the back, for the ride in the outside hilly terrain it is better to have a wheelchair with bigger wheels at the front. Other properties which need to be taken into account at buying a wheelchair, are sitting height, decomposability of the wheelchair, spaciousness of the sitting surface, full leaning of the back, bearing capacity, supplements, work board. Wheelchair should not be too deep for avoiding of deformation of the sitting position. Patients should have a possibility of trying a wheelchair before they buy it. There are often cases, where bad selected wheelchair worsen the state of health of the patient. Anyway, patients have entitlement for a wheelchair only once in five years (in the Czech Republic), and if they cannot allow to pay it themselves, they have to use it even if it is bad for them.

Other locomotion tools are different bicycles, tricycles, scooters. They are suitable for people with walking dysfunction (stumbling, ataxia, unsteady, stiff walking), where a strength in legs is remained.

For dressing, there is a tool for doing up the buttons, dressing of the stockings, doing up a zip, fastening on patents, Velcro, drawstrings, hooks, buckles, shoehorn, bootjack. Patients and their relatives in the Czech Republic have very low awareness of these tools, though they would facilitate their life very much.

As far as the personal hygiene is concerned, we could give an example of back brush or washing sponge with a prolonged grip, strengthened grip of a comb, tool for cutting nails with fixed to the table, stool in the bath or shower, small steps into the bath, nonskid mat, horseshoe for sitting on the toilet, rest in the toilet, bidet, feeder of soap and toothpaste.

Regarding tools for preparation of food and self-feeding, here belong adjusted cutlery, combined cutlery, specially shaped grip of the cutlery, spring handle of the cutlery, chopping board with spikes and fixed to the table, separator of yolk and white, electrical kitchen appliance (beater, kneader, dasher), hinged handle of a pot or a glass, scraper for vegetable with a hitch, kerb of a plate, nonskid mat to be put under the plate, openers of screw-on thread, bottles, cans, holder for straining off water from boiled food, tea trolley. Nor these compensatory tools are common in the Czech Republic and many people do not know about them at all.

Concerning the tools for home works, it includes for example: brush with suckers, sweeper and trowel with joint or prolonged grip, set of bucket and mop, collapsible ironing board with adjustable height, tool for threading, special scissors, etc.

For the common activities, here belongs training board, scissors feeder, Swedish feeder, holder of pencil, cards, telephone receiver, book, shopping trolley, nonskid mats, sucker tools, holder of keys.

A useful tool is also information on how to create a home environment without unnecessary barriers. Floor should be smooth, without projections. Furniture should be arranged synoptically, single parts of the furniture can be used also as support points, also the right height of the furniture and storage space should be chosen. In the kitchen, they should place backrests, bars, handles, stool, small steps into the bath, jack, nonskid mat, and stool in the toilet. Bed should be accessible from three sides, comfortable, spacious, solid, airy, 50 cm under the floor, also may be

equipped with rubber underlay, urinary bottle and underlying bedpan. Small ladder or horizontal bar can serve to a better locomotion. Supplementary equipment can include night table, work or dinner table and tool for positioning (heightened support, cylinders, small box, bags with sand, antidecubital underlying).

Information about tools should be complemented with the information on the conditions given by law, under which the tools can be obtained. This means which tools are covered by health insurance as well as information to which extent are the expenses covered by health insurance and which are covered by social department. This minimal knowledge should as well be extended to the issues of social care, the list of allowances and favors available. Because of the legislative differences among states, this part should be processed by each partner for his own country.

These are the information that patients and their relatives ask for the most frequently, along with the information on multiple sclerosis itself.

Taking into account that MS influences not only the health of the patient, but has also different psychosocial consequences on patient and its environment, these impacts should also be mentioned on the CD.

The uncertainty and fear, which follows the diagnosis of MS, can deeply impair the family relationships. There is an increased number of divorce rates among the families with MS. Those who are diagnosed with MS in young age, find it often hard to find a partner and stay in parents' care.

Facing the new life with MS, not only the patient, but also his/her family members (specially partners and children) have to cope with the new situation. When a patient with MS feels he/she did not get the sympathy and understanding he/she was looking for, he/she often tries to manipulate the family to get what he/she thinks is his/her right to receive. And it does not depend, whether the lack of understanding is true or only a subjective feeling. This manipulation can grow to become the emotional blackmail and terror of other family members. The only solution to this situation is the assertiveness training of all family members, teaching them how to communicate their feelings, wishes and hardships in a calm, non-accusatory way. The family problems can

arise easily when patient is in an early stage of a disease. Sometimes the family members may think the patient simulates the disease to receive the "advantages" they are not "entitled to". The help here lies in the good knowledge on the disease and its manifestation.

MS definitely influences all family members, like any other chronic disease. It reduces the life, as well as life of other family members, and mainly the free time partners, who suddenly have more duties in the family. Partner is in the situation in which he/she is expected to restraint his/her emotions, to be extremely tolerant and patient and to follow the needs of a patient. Also, the lower financial income leads to the decrease in the familial standard of living.

The partner and patient should know that there are entitled to their own life, their privacy and their time which they can spend with their friends or alone. They should not change and/or lose their friendships and social contact. They should know that the feelings of guilt they encounter when they argue with the patient or their feelings of being used are normal. These negative emotions belong to the process of adaptation with the disease and they are nothing to be ashamed of or feel guilty about. They should have friends who can listen and discuss these feelings. The partners/guardians should spend some time apart from the patient; spend a week-end alone or with their friends. Also, they should not decline all offers of help or sharing the care of the patient - their partner. And the patient should, as well, understand that it is normal, and he/she is not left alone with the disease, or feel unloved when temporarily left alone, and the patient should also understand that the guardian needs the rest and free time he/she deserves.

If the partner is under pressure for a long time, he/she will stop providing the support and help. Even the support of the doctor should be given to the partners and guardians, as well as the patient himself. For this purpose and support, the self-help organizations exist.

The self-sufficiency factor is a very important part of life for MS patient. It should always be encouraged by patient's family. Self-sufficiency increases patient's self-esteem and plays also a rehabilitation role. With some tools, the patient can do what seems impossible at first. The self-sufficiency training in daily activities and choosing of appropriate tools is the work of ergo therapist. A part of self-sufficiency is the daily hygiene and care for one's appearance, which adds to patient's self-esteem and to the preservation of the person's integrity.

In the opinion of the participants, children should be told about the disease, they should get the information about the disease accordingly to their age and their understanding. When the disease is a taboo, the child perceives the atmosphere of fear and he/she can feel guilty, because he/she may think he/she is responsible for the disease of his/her parent, or that the parent's care of the child is too exhausting for the parent. It is very advisable to let the children know that there is a lot of people who must use the crutches or a wheelchair because of their illness, and that this is not a reason to be ashamed of one's parents. In relation to the parent's disease, some duties are delegated to the child. Here, the right extent of responsibility must be found, in order not to load too much upon the child.

All interviewees find it very important for a patient with MS to work. If the case is that the patient loses the job, it usually very negatively influences the mental state. While in the past the MS patients were almost automatically filed in the invalid pension scheme, now the trend is to have them work as long as possible. It helps their mental agility and physical condition. Sometimes, it means to agree with the employer on a part-time work or on working from home, if the nature of work allows so. Another time it is necessary to find other, more appropriate employment.

To motivate the employers to hire people with disabilities, the legislation had been provided that states that organizations with more than 25 employees are obliged to employ the disabled persons, with disabled workers to be at least 4 percent of the total number of employees. Furthermore, there are possibilities for employer to receive a financial contribution to create a "protected workplace" for a disabled employee. That is why the CD should contain this information (unique for each country), so that the MS patients and their family members can use this information as arguments during their search for work. It is also important for a patient to keep his hobbies and to be active.

Some recommendations and advice on how to live with MS are important: the life with MS brings many questions that patients and their family members need the response to, and which are not included in the previous chapters. They cover mostly the following themes:

- diet - which diet is appropriate, and what is the expert's opinion on various diets?
- pregnancy, contraception and menopause - how do they influence the life and treatment of a pregnant patient?
- hospitalization and surgery for other health problems - what is specific for MS patients with other diseases?
- drinking and smoking - what is the attitude to be taken towards drinking and smoking?

This chapter could be expanded by a number of other themes, e.g. MS and sexuality, sleep, the social life and many more.

Moreover, the patients and their family members very often inquire about the organization working within the field of MS that can be of help to them. An address book of these organizations should be a part of the CD, which will, however, be individual for each country. The list should be composed of the short description of each organizations' activities and contact information. For the Czech Republic, the following groups of organizations and information sources should be included:

- Medical centers for MS, focused on diagnostics and treatment of MS – contemporary 13 workplaces
- Patient and support organizations – more than 30 branches of Union Roska and other organizations
 - Consultancy services
 - Spa treatment, rehabilitation stays – overview of institutions that offer spa treatment and rehabilitation stays
 - Social services – overview of institutions that offer social services
 - Literature about MS – overview of available literature concerning MS, information on lending conditions in the libraries

The participants of the interviews appreciated the increased volume of information that can be found on the internet, thus becoming the main source of information for many of them. This is the reason the CD should include the chapter on the information sources that can be found on the

internet. This chapter should mention the main international servers dealing with this issue, as well as local information sources, the list of which will be produced by each participating country.

While informing about MS, it is impossible to avoid all terms, which may not be known to all users. Therefore, users will welcome a small dictionary of terms used during explanation; the best solution seems to be to insert the "bubble-help" explaining the terms right by the text.

3. QUALITATIVE RESEARCH IN GREECE

3.1. Interviews.

In the qualitative research carried out in Greece, there have been taken six interviews by individuals that are specialized on MS disease.

The participants were the following:

- Two doctors (neurologists experts in multiple sclerosis).
- Two physiotherapists (also experts in neurological diseases).
- One ergo therapist.
- One physical trainer (specialist in multiple sclerosis).

Due to the variety of expertise Greek partners tried to gather many different opinions, as well as different kinds of help that is asked possibly by the relatives.

As main conclusions of the interviews, and taking under consideration the interviews of the two doctors, (both neurologists-psychiatrists) concerning the activities / actions that have taken place and have participated only relatives of patients with multiple sclerosis, six years ago tried to do a “psychotherapy group” for relatives but it couldn’t keep up because of the lack of the foundation. In the past there had also been organized sessions in order to inform the patients, in which the relatives were informed too. We have to add that among those things has been done a research project totally for the children whose parents are MS patients. Of course, there is at the libraries the so called “green book” for the people that take care of patients with multiple sclerosis, who most of the time are indeed their relatives. Generally though the suitable foundation that would help, the patients and the relatives, to manage with the problems caused by the disease, does not exist.

The relatives do not get any economical support for the care that they give and the only help is the disability allowance of the patients. Generally, it is not predicted by the laws of Greece this kind of economical support, although is a good idea for the effort that Greek Multiple Sclerosis Society is doing, for the legislative regulation at national and European level. In conclusion, the doctors usually advise and inform the relatives in matters of psychological support, since this is the main help wanted.

Beyond the psychological support, that relatives ask for, there is a big need for help for solving the daily problems, one of which is transportation. Answers to the above subject were given by physiotherapists and ergo therapists that are experts at this disease.

The activities – actions that have been organized systematically in Greece for the education of relatives of patients with MS in subjects such as transportation are very little. For example, there was only one project that tried to show to relatives how to pass through not approachable places, such as stairs. It is a fact that there is ignorance and lack of knowledge from the relatives in this specific field. If they acquire knowledge of this area the relatives will be able to improve the quality of life of the patients. Despite the above, Greek MS Society has tried to provide this knowledge to the relatives through seminars that were held out in times. The fields the GMSS tried to help in, were psychological, medical and physiotherapeutic.

There are no motives to make the relatives search the knowledge in these fields, but on the other hand no one has emphasized this side of the problem – the relatives- until now. Due to their ignorance they are not asking for help or information in all the fields, but in specific. One of the physiotherapist emphasized that almost all the relatives were asking for information about the economical support that they can have from the state.

If there is motivation, although there is no educational base in the majority of the relatives, they can be trained in different areas subjects good enough.

In conclusion, all experts agreed that the psychological support of the relatives is necessary, as well as their training in subjects concerning their daily problems such as transportation and self-service. Also is a fact that the relatives are not trained in fields that are necessary for the easier confronting of the disease. But this is a matter of willingness.

Concerning the economical support, beyond the disability allowance that the patients take, there is no help in Greece, exclusively for the relatives for the job that they are doing, helping their patients.

The need to help the relatives is apparent because through our help they will be able to know the disease better, and then they will be able to behave in a better or proper way in order to help the patients.

In the end, there is a big need to help the relatives of patients with multiple sclerosis in all the areas, with emphasis to the fields of psychology and transportation.

3.2. Focus Groups.

- Focus Group with the relatives.

The participants were the following:

1. Katerina, her sister is patient with MS (high level of autonomy). Single, she lives with her sister who is a patient.
2. Helen, her husband is patient with MS (medium level of autonomy). She is married, with one child.
3. Katerina, her daughter is patient with MS (high level of autonomy). She is married, with two children.
4. Sakis, his wife is patient with MS (medium level of autonomy). He is married, with one child.
5. Anastasios, his daughter is patient with MS (medium level of autonomy). He is married, with two children.

Concerning the labour situation before and after the diagnosis, the answers of the participants were the following:

1. She has a school with computers. Before the diagnosis she and her sister (the patient) had a shop with alcoholic drinks. She closed the shop after the diagnosis.
2. She didn't have a job before and after the diagnosis.
3. She is owner of a clothing shop.
4. He is a seller in a private enterprise. He works there before and after the diagnosis.
5. He retired 5 years ago because of the disease of her daughter. He used to be a worker.

As far as the MS disease's influence in the family and personal situation of the relative, their experiences were the following:

1. There was no significant difference after the diagnosis. She used to live with her sister as she does now. The only difference is that she has to clean their house on her own. She cannot think to married because she believes that she has to take care of her sister.

2. She got married before the diagnosis. Still she is married with a lot of problems. Due to the loss of the memory, she reported major communication problems with her husband (the patient). This is tiring for her because she doesn't know the way to deal with it.

3. She reports no change in her life after the diagnosis. She is a widow and she lives alone. Her daughter also, lives alone. Sometimes she feels bad about the disease, but in front of her daughter she plays theatre and never express her true feelings.

4. He didn't change his life after the diagnosis of his wife. He tried to learn more about the disease from the internet. He is trying to be positive and giving courage to his wife, but mostly to himself.

5. He used to live with his wife at the first years of the disease (his daughter is a patient) but the last 7 years live all together. He reports no change in his personal life apart from quitting his job.

They faced their daily activities as shown below:

1. After the diagnosis she had to decrease the working hours in order to dedicate more time to her sister. Also she has to do the housework and she get tired all the time. She feels that she has no time and courage to do something for herself. Also she complains that she has no financial and psychological support to deal the daily problems. Luckily, her sister is in a high level of autonomy and she has no need of transportation.

2. She does the housework on her own and she is 63 years old. She feels very tired and disappointed with her life. Despite her husband's care, she has to take care her sister in law too. She faces many difficulties but she doesn't want any help because she wants to prove that she can manage all these.

3. Despite that she is going to her daughter's house frequently to clean, and calls her 10 times per day to see how she is, there was no change in her daily life.

4. He understands that his wife cannot manage the housework, so he pays a woman to do it. He reports that he feels terrible seeing his wife in this way and he doesn't know the way to deal with. He wants psychological support and also some financial support.

5. Because he retired he is the whole day at home and he understand the difficulties of his daughter. Fortunately his wife, and her mother, is very supportive, helpful and very attached to her. He didn't mentioned any financial problem, but he underlined the transportation problem because of her ataxia. He concluded that he needs, definitely, psychological support to face the disease better.

Concerning the educational background of the participants, three out of five relatives said that they neither had the acquiring experience, nor they were trained on how to provide help to the patients. The only education they have on this matter is through some seminars and scientific magazines of GMSS. Because of their ignorance in all the scientific fields that have to do with the disease, these people are frightened for the further more evolution of the disease, and also for the way that they treat the patients, whether it is the right way or not. They believe that if they get some education about the disease, they will be able to confront easier some behaviors that will probably come up. IN conclusion, all the participants admitted that they need psychological support.

When they spoke about the educative material that is considered to be proper for the education of MS patients' relatives, in their opinion a good idea could be a DVD with pictures and videos where they could take some information about everyday activities. Also some physiotherapy exercises could be included in it. The problem that was emphasized by the relatives mostly, was the need for help in the psychological field. So, some psychological information could also be useful.

- Focus Group with the people suffering MS.

The participants were the following:

1. Dimitra, 6 years with MS, high level of autonomy. Divorced. She lives alone. She does not have any children.
2. Helen, 25 years with MS, medium level of autonomy. Married with one child.
3. Eugenia, 24 years with MS, high level of autonomy. Married with two children.
4. Andrew, 23 years with MS, medium level of autonomy. Married with three children.
5. Constantine, 20 years with MS, medium- low level of autonomy. Married with two children.

Concerning the labour situation, both after and before the diagnosis of the participants, their remarks were the following:

1. She is a hairdresser. She stopped working one year ago. The disease was the reason for quitting her job.
2. She used to work as a schoolteacher. She has stopped working, a few years ago, because of the disease.
3. She used to work as a professor. She stopped in 1993, because of the disease.
4. He was a sailor. He has stopped working for one year now. He had a hard time because of the disease. Additionally he couldn't find a job because he has ms.
5. He is a lawyer. He no longer works because of the disease.

When speaking about the MS disease's influence on the family and personal situation of the patient, they said the following:

1. She was married. After the diagnosis she thought that her spouse could not cope with the problems and the requirements of the disease. The communication problems that they already had grew bigger and they divorced. Now she lives alone, while her other family members live in another city. At first she kept the disease secret from her parents. Because of the fact that she lives alone and has quit her job, she is in a financial difficulty.

2. She got married after the diagnosis. The birth of her child made her health condition worst. She considers her husband to be overprotective.

3. She reports no change in her life after the diagnosis. She says that in the beginning she wanted to keep her children away from her disease, she understood that this was a big mistake and changed her mind. She considers her self to be the source of power in her family. She gives courage to the other family members.

4. After the diagnosis he changed place of residence, in order to find a job more easily. After the diagnosis he had a third child. He considers his wife to be the "leader" of the family.

5. He reports no change in his personal life, apart from quitting his job. His family went through an adaptation period but they managed to find their balance.

Concerning the daily activities, these patients' experiences were the following:

1. She lives alone so she has to do everything on her own. She has been forced to find several "tricks" in order to cope with her daily needs. For example she uses nippers to turn off and on the washing-machine, because of a weakness she has in her hands. She cannot deal with the heavy housework, e.g carpets, curtains, weightlifting, so she pays someone to do them for her. She has horrible insecurities for her future because of the disease. She feels depended on her sister who takes care of her and supports her financially and psychologically. For her daily needs – mainly for transportation- she asks for help from her neighbors, e.g. in order to go up and down the stairs, to use the bus or go across the street. Tiredness is the bigger problem for her, so she avoids doing certain things or makes frequent intervals when she does the housework. However, she reports that she manages things very well on her own.

2. She pays a woman to do the housework. She reports that even though she knows she can do some of the housework, she deliberately refuses to deal with them. She feels much depended on her mother, despite the fact that she is a married woman with a child. Her mother is very supportive, helpful and she is very attached to her. She sometimes uses a walking stick. She

mentions tiredness as her greatest problem. She faces many difficulties on issues of personal hygiene, but denies receiving any help.

3. She finds it difficult to go up and down the stairs, therefore she needs help. She pays a woman for the housework but she also deals with them, as much as she can. She reports that even though she doesn't ask for any help, all the members of her family undertake certain responsibilities, e.g. cooking – mainly her children because her husband works many hours. She states that she does not feel dependent on no one.

4. He reports that he actively participates in all the housework, as much as he can. Further to our discussion he reports that most of the times his role is limited in supervising. He feels great insecurity for the future of his family and he is supported by his wife.

5. He reports that there are many difficult days. His wife has undertaken the role of the "leader". Sometimes he cannot get off the bed or he falls off the bed during the night. His wife and children help him with everything.

Although the question was repeated several times, none of the participants reported a lot of details with regards to the activities of their everyday life. They all mentioned there are many difficult days, but no one spoke extensively about them. They focused mainly on the things they can rather than they cannot do.

Regarding their relatives taking care of their needs, all the participants agreed that what should be done to make things better is a better economical provision from the State. They report that certain benefits for treatments, auxiliary equipment, also for care givers for them and the house are essential. No one would like for their family to burden their care and they wish they had the possibility to have other individuals do certain activities.

All agreed that they need their families and that their relatives who take care of them need psychological help, proper information and education. They have mentioned some cases in which families were separated, because the spouse couldn't accept the disease of their husband/

wife and couldn't cope with their needs for care. It was mentioned that the financial problem is the usual cause for divorces.

As far as children are concerned, all agreed that they should be fully informed about the disease and share the needs of their families.

They wished that there were better measures taken by the State with regards to the provision of information and psychological support of their relatives, but also for the entire family. They all feel dissatisfied with their doctors, who do not deal at all with the sentimental dimension of the disease.

It was mentioned that they would like from the government to concede them transportation means specially adapted to their needs. Also that the pension and the allowance they take are not enough to cover their everyday needs as they want to be able to improve their social life.

All reported that they would want the society to be more informed with regards to MS, so that they do not treat them with pity and bias.

The most important issue was reported to be that they have to be examined by a medical committee, every two years, in order to keep receiving the allowance. Due to the instability of the disease, they would like to be examined once and keep taking the allowance lifelong.

As far as the care background of the relatives is concerned, apart from Katerina whose sister is a nurse, and has a care background from her studies and work, no one else's relative has a training background for taking care of a patient with ms. They all reported that experience and their daily care activities taught them how to cope with their daily needs.

When talking about the influence the lacks and difficulties of their relatives on the patients have on them, they all feel bad about the fact that their relatives have undertaken so many care responsibilities. They feel compunctions, but they also feel anger, because they think that they cannot understand their needs.

In order to cover those lacks, they propose the following:

- Education and briefing of the relatives
- Financial aid for the help they provide
- Help from the state, that is to provide services that will help them in their tasks
- Creation of public and completely equipped rehabilitation centres

A proper education material for the education of MS patients' relatives could be a CD- ROM with practical information about everyday activities, it was considered to be a good idea. What they think is mainly needed to be done is the provision of information through the Media, in order to reach all the interested individuals/ authorities without any exception.

4. QUALITATIVE RESEARCH IN ITALY

4.1. Interviews.

Following the project analysis design six interviews were performed with professionals working with persons affected by MS pathology. The persons were chosen on the basis of their experience, their effective relationship with the interviewer and their availability for the participation to this study. Each of them was characterised by a different experience in working with PwMS and in general they, (although belonging to the same sanitary structure) are not working together (in the same working group) normally.

Below we list the names and the professional figures of the interviewed persons.

1. Medical doctor, neurologist. Responsible for the rehabilitation dept. for the area of central Region Umbria (ASL n.3)
2. Medical doctor, psychiatrist. Responsible for the MS caring center of the central Umbria Region.
3. Medical doctor, neurologist. Responsible for urological treatments for MS patients in ASL n.3
4. Occupational Therapist. Working at Terni - rehabilitation centre S.Maria
5. Psychologist. Working also at social dept. of ASL n.3 of Umbria region.
6. Psychologist. Belonging to PRISMA association of Foligno (association of families of PwMS).

The opinions obtained from the participants will be explained individually one by one:

1st participant.

Neurologist, the tasks he carries out concerned the management of assistant and care for MS and direct specialist counselling to patients and their care givers. Moreover, concretely dealing with MS, he carried out evaluation visits, in-hospital evaluation and specific assistance. Concerning the necessary skills for carrying out his tasks, he explained that the relative usually learn from the nurses and physiotherapist during the in-hospital period of the person. It means the

execution of practical tasks under the direct supervision of the "teachers" in order to confirm the correctness of the operation. Anyway, he added that this practice does not represent the common practice in Italy, there are no standard about and each centre of care is operating in independent way.

He meets periodically relatives of persons with MS, this meeting normally is not a specific meeting, but is in presence of the patient himself. In some specific cases the training could be proposed at patient home. The personnel involved in this education path is composed by physiotherapist and psychologist of the rehabilitation centre, specialised for the treatment of persons affected by MS.

Concerning the possibility of transferring the caring tasks to the family member, he thinks it is possible to provide education basis for training to relatives using paper based material as well as multimedia courses (CD or DVD. The materials needed for that could be based on paper or CD ROMs. Moreover, he said that patients could not receive an economical support to help them to buy such material/course in Italy.

2nd participant.

Physiatrist, he carries out the counselling and prescription of drug and specific technical aids, regional reference for the sanitary/health services for the problems related to the MS. Moreover, he is responsible for the prescription of drugs for MS patients. All the patients are inserted in a specific rehabilitation project, including both in-hospitalisation and day-hospital of the person. (it depends on the severity of the condition of the person). Many: attention to the psychological factors, physical conditions...

The relationship with relatives is constant and more and more confident/personal as well as the progression of the disease produces disability and a substantial reduction of the autonomy of the person. Relatives are supported by means of a direct counselling about drugs, therapeutic advice, practical advice about management of feeding (nutritional problems) and any other problem they could face. During the in-hospital period, nurses teach relatives about operations to be done at home (safety, accuracy...).

With the aim of transferring the knowledge of the professional caring tasks to the family members, the idea of a handbook could reduce the relationship among the clinical centre and the patient/relatives, giving the idea "to do all by themselves"... It could be utilised as reinforcement of the treatment already provided (in order to help relatives). The interviewed seems to be concerned about a simplified and not personalised approach provided by a generic manual. The materials could be what already transferred by nurses to relatives (in oral form). It is very important to have a direct training (seeing at operations..) rather than an information/learning based on the description... It is very important to have a direct training rather than information / learning based on descriptions. He thinks there should be specific supports for buying these courses, since there is nothing.

3rd participant

Neurologist, operating at Trevi Hospital, gives assistance and counselling and is responsible for the in-hospital rehabilitation department. Moreover, he offers assistance and counselling to patients suffering MS and in general to those affected by neuro-urological disturbs.

His relationship with relatives is strict and continuous, cause they are often involved in the management of problems (also neuro-urological). They have to be active part in the information about these problems as well as in the management of these at home. Both patients and relatives are informed about theoretical basis of scientific type on the management of the problems and why it is important to pay attention to monitor their evolution. At the end, they learn to use the necessary instrumentation for therapy/autonomy purposes. Nurses provide the education course for relatives and patients

The most requested helps are based on the need to control the functionality of the urinary apparatus taking into account the practical management of drug treatment at home (time, doses...). In his opinion, it is possible (via paper material) to acquire basics about pathology, risks and consequences in the middle time and at long time effects. Some videos could be useful to acquire practical information. An idea could be to integrate this tool with some informatic tool for the communication with the clinical centres (records to be filled in...to store the daily activities).

There is a general skepticism about the idea of a multimedia tool, caused by the experience and the relevance of families with low/no computer skills due to cultural/economic/age condition.

4th participant

Physiotherapists specialized in Occupational therapy, he works at Terni rehabilitation hospital, carrying out concrete therapies for motor and cognitive activities. More concretely, he deals with functional management of motor autonomy of people with MS.

Some patients are assisted in specific structures so the relationship with their relatives is weak in his case. Most of the patients are in a good cognitive status (they are able to express their opinions/wills even with movements). Physiotherapists normally teach relatives about the exercises to be performed at home, in order to reach a good exercise (correctness). These exercises are useful for the autonomy of the person.

Concerning the help provided by the professionals, he said that only in few cases a domiciliary (at home) assistant is supplied to relatives, due to problems related to the costs of these activities. The helps asked for are very different, but it is interesting to mention that as the relatives become experienced about the disease, they produce more detailed requests.

The best solution could consist in supplying a handbook composed by different cards including a video recording for each. The exercise is normally of different type and different level of difficulty, they could be described in the written part and displayed in the video. Each card should be referred to a single exercise.

The patient normally follows with accuracy the prescriptions when he is constrained to collect the daily activity (related to what is requested) in a recording tool (written/computerised..).

5th participant

Psychologist, working at the social department of health service in Umbria, carries out group psychology, work psychology, evaluation of effectiveness of social assistance services, as well as

evaluation and psychological support of patients affected by MS in-hospital for a period of time minor than 1 month in a rehabilitation centre.

The relationship with the relatives is mainly related to the family care givers, on the basis of their requests. Relatives find difficulties in facing the disease, (with all the consequences and doubts about the future of the person) and the variation of the humor/feeling of the person inside the family. It is very important that relatives were informed about the disease and its possible consequences, in order they are able to face it and evaluate their own responses at the specific crisis or period of time (this self- evaluation comes with the awareness). It is important to analyse the influence of the disease not only w.r.t. patient, but also in relation with the family (how it reacts to the new-mutating situation).

Concerning training materials for the family, it is hard to involve families at the beginning of the disease with a direct course (frontal lessons), a better strategy could be the instruction via handbook (paper based). On the other side (no handbook and information meetings), should be useful for families that experience since a long time the disease. Anyway, she showed a kind of scepticism about the usability of a CD-ROM instead of paper based material (cultural level of families involved in SM).

6th participant.

Psychologist, specialized in family support, he offers counselling in psychological support and therapy.

Concerning the individual tasks regarding patients with MS, he carried out individual therapy and/or couple therapy about relational problems due to MS illness. In most cases the person with MS has the tendency to unreveal the illness till it is in a first stage (without limitation of the autonomy - low level of disability). This behaviour is due to an anguish-bad feeling too heavy to be solved in the relationship of the couple (with the other partner alone). The intervention of the psychologist helps both to talk about the illness treating this shadow between them: it helps the partners to discover a new way to participate to the situation considering the future evolution of the personal condition. The need to give an help to the relationship between the partners (before

than the rest of the family) is important and urgent. The problem is that the presence of psychologist is fundamental for the efficacy of that

This person has continuous relationship with the partners of the persons with SM (not other relatives), during the activity in Trevi hospital as PRISMA association specialist. The most requested help usually concerns the relationship between the partners (before than the rest of the family), he said it is important and urgent. Negation of the disease seems to be the main problem: the psychological status of the patient is the origin of this problem. Without acting on this status there is no way to change the situation (no handbook, no CD..), all the interventions could be un-useful.

4.2. Focus groups.

The Focus Group with the relatives of people with MS in Italy was held on the 3rd of June 2005 from 17.15 till 18.45 at U.O.R.I.N. in Trevi.

Dr. Mary Micheli was present as chairman and the nurse Anna Rita Muzzi as observer.

The relatives of people with M.S. were the following:

- A: Santina (sister of a person with MS),
- B: Paolo (husband of a person with MS),
- C: Fausto (husband of a person with MS),
- D: Luciano (husband of a person with MS).

A relative reported at the last moment that he could not come and another one did not appeared.

Dr Micheli, after having presented herself and after having explained the object of the Focus Group, asked each of those present to put their signature for the authorization of the audio-recording and, consequently, she started the recording.

Concerning the influence of the disease on the family situation, their comments were as follows:

A: The illness had been diagnosed two years ago when the woman was 45 years old. They had two teenagers and it seems that the illness has not influenced the family situation but for a greater engagement of the husband, who, now, is therefore obliged to help his wife in the housework.

B: Is the sister-in-law- of A. Being external to the family her contribution in this group has been not much remarkable.

C: The illness has been diagnosed five years ago. They have got two children: a girl who, married for short time, has just born a child and a boy (about 20 years old.) who is remained “exigent” as usual. Even the mother of C. Leaves with them (with the Alzheimer morbus). The illness has stressed the relational problems between daughter-in-law and mother-in-law and this fact drives C. to a continuous mediation between the two women. He is the only one who takes care of his wife, of the housework and of the family.

D: The illness has been diagnosed in 1992. Also they, they have got two children but just like every child they have their life and they live the illness of their mother only marginally. (Thus she says). The woman seems to have a lower level of autonomy in comparison with the other women, but also in this case the only person to look after his wife, his house and his family is the husband.

As far as the influence on the labour situation, they discussed the following issues:

A: He is a lorry-driver (he transports gas bottles). The illness of his wife has not influenced his work. The difficulty is to conciliate the hard work with the apprehension for his wife, staying at home all alone, and the demands of the family.

C: At the moment he does not work but not because of the illness of his wife. He had got a knitwear factory which he was obliged to shut down (the tendency of the market). He has been six months abroad as an engineer and now he is waiting for the opportunity to come back there. He doesn't believe that the illness of his wife may hinder him: it will be sufficient to find a person able to keep company to her and to his mother. He prefers to go back abroad, even if for a short period, rather than being a worker here.

D: He works and takes advantage of the Law 104, 5th of February 1992, which allows her to absent herself from work three days every month. Sometimes they are not enough for her, but she can't manage in a different way.

Next topic to talk about was the cares given the patients, and their answers were the followings:

A: His wife does not need, for now, different kinds of treatment. The woman is still quite self-sufficient but she soon gets tired and she is often forced to have a rest, so that it is above all her husband who is busy about the house.

C: His wife has been completely paralyzed and therefore hospitalized, only during the intense phase of her illness. With cortisone she has really recovered her health thus she doesn't need a particular treatment. At home she can move rather independently even if her bedroom has become her only world: in there she feels secure (maybe also distant from her mother-in-law). The greatest task of her husband is to find at all times friends able to entertain her and to get her rid of loneliness. With other people she feels more active, even if she pays her best attention to all that she does.

D: The woman has got very limited moments of self-sufficiency but in those instants she can take care of herself autonomously: the assistance of her husband is requested only for the bath. Mr D. Has taken a lot of trouble to make his wife as much self-sufficient as possible by making several restructure housework: first of all they have chosen a house on the ground floor, then he has adapted it (day after day) to the different needs of his wife with banisters which could let her to reach the garden and to move inside it. Just nowadays he put up an electric curtain to shelter her from the sun.

Concerning the caring background of the participants, all people agree upon the necessity of having information and everybody, a part from those received through the sanitary staff at the very moment of the diagnosis, has found the news in a different way: A. Through a book, C. through her sister, by internet and by television programmes, D. Through a doctor friend. A. seems more interested in gathering information about possible care, C. asserts that in any case very much depends on the person: it is not possible to affirm in two, three, five years' time.....D. admits that he knew but he didn't think of it: as time passed his wife has given up a lot of activities, someone had told to him but he didn't expect this. All people agreed upon the necessity of comparing themselves with their daily: all seem frightened for what the future could reserve them and they had rather not to think of it: they face the problems at once. The news is useful in

order to make the sick person accepting her illness: “if you fight it, you live better!”. He who lives nearby an invalid must accept the illness without making falling the blame upon the sick person.

As far as the difficulties are concerned, some of them said that every day you must learn a new thing. The relations with people who don't understand the demands of a sick person: there was a co-owner who has not accepted the curtain to shelter the sun which let my wife to go into the garden without remaining all day at home.

Next, they discussed about the possible means to solve the lacks, for which they said that these persons have not to isolate themselves, but they always should have someone to keep them company: in this way they can do their best.

We can conclude by dwelling upon some points:

- From the Group it has emerged how it is difficult for the relatives who take care of persons with MS talking about themselves and about their own problems: they all make reference to the person with MS: this person needs help, they managed to get along all by themselves as far as possible.
- As for the news they could receive about the illness, they all agree upon the importance of having such information and all of them, in different ways, have received them. But it has also come out that till when particular conditions appear, one do not believe it.
- Compared to the possibility of personal training, the unanimous answer has been that one realizes the different needs of the sick person day after day and it is just at the moment, at one's daily, that one must act: the previous day one cannot know what could “serve” in the following day. This sort of behaviour hides a deep anguish for the future.
- The greatest difficulty is the fact that it is an unforeseeable illness and also the fact of trying, all day, to pretend not to see (in the presence of the sick person), even though one can see the continuous “aggravation” of the beloved person.

The emotional feelings of the people participating in the group were mostly resignation, anger and tiredness.

5. QUALITATIVE RESEARCH IN SPAIN

5.1. Interviews.

The interviews in Spain were carried out in three different cities (Bilbao, Madrid and Palma de Mallorca), making the most of the fact that there were four Spanish partners. In all, 16 interviews were carried out, and the profiles of the participants were the following:

- 1 Nurse, working at the MS day-centre in Bilbao.
- 1 Domiciliary assistant, working at home of the people with MS, from Bilbao.
- 1 Nursing auxiliary, working at the centre of Madrid.
- 2 Physiotherapists, one working at the MS Association centre of Palma de Mallorca, and the other one in the centre of Madrid.
- 2 Speech therapists, one working at the centre of Mallorca and the other one in the one in Madrid.
- 1 Doctor, attending the centre of MS of Madrid,
- 1 Neuropsychologist, working at the day-centre of Madrid.
- 3 Psychologists, one from each participating city.
- 1 Occupational therapists, working at the day centre of Madrid.
- 3 Social workers, one from each participating city.

Here we summarize the answers and information given by them to the interviewer, stressing the main conclusions.

The Nurse from the day centre of Bilbao, was mostly in charge of assisting people and covering the needs of the patients. She tries to give the first help, so that the relatives can help then at home. She thinks that the relative must have real information, studied and contrasted, and must be able to adapt this information to the relative, according to the symptoms. The necessary real skills would be to be able to make a sounding and cures, so that it why they try to involve the main care giver. Usually, most requested help by the relatives deals with the following topics: incontinence, treatments, catheter positions and how to use the medicines, and according to the opinion of this professional, it can be quite easy to transfer her knowledge to the relatives if they have interest in learning, but always with the supervision of a professional person. Concerning

the possible means to transfer the knowledge, it is very important to inform the relatives about where they can find information about MS and how to use and interpret it.

The Domiciliary Assistant from Bilbao was in charge of assisting the person with MS at home, since this way she can realize about the instruments and the means the patient has at his / her own home. Her tasks usually are the following: to help them getting dressed, to give them breakfast, to come with them for shopping or for a walk, and so on. She thinks that it is essential that the relatives have a background regarding the illness, as well as psychological support, but anyway they should always have the supervision of professional people.

The Nursing Auxiliary was from Madrid, whose job was focused on helping the patient to become as independent as possible, make his / her life easier. Her relation with the relatives of the patients is very close, as they always ask for advise, mostly dealing with incontinence, transferences, how to move the patient and choking.

Concerning the contributions of the two Physiotherapists interviewed, the relatives always need help concerning how to move the patient, in order to avoid being hurt. For this aim, the most helpful means would be some training materials with a lot of practical cases and pictures, as this is the best way for understanding the positions. Both of them agreed that the most requested help by them deals with the available technical instruments for moving the patients. In their opinion, the suitable support for teaching this kind of subjects would be some videos that the relative could see at home with a lot of practical cases.

As far as the Speech therapists are concerned, their tasks are related to evaluate the disorders of speech, for which they have individual sessions with the patients. But it is interesting to stress that the first visit to the consultation is always with at least one of the relatives. They offer guidance concerning communication with the patient, drinking, eating and breathing, as these topics are usually the most controversial ones. Regarding the training the relatives need, it mostly deals with the proper positions and habitudes of the patients when swallowing or breathing.

One doctor was interviewed, who works in the Day Centre for MS patients in Madrid, and he said that his relation with the relatives was very close and continuous. The most common questions the get from the relatives deal with the movements of the patients, the transferences and the diets they recommend. In his opinion, the support and some training is more necessary at the beginning, that means just after the diagnosis, as this is the most difficult period for the relatives. Then, the necessary training deals with other aspects of adaptability, such as wheelchairs, instruments for eating or for personal care.

Next interviewed was one neuropsychologist from Madrid, whose tasks were the detection of the emotional and cognitive disturbs. Usually, the relative is present since the first visit, and the most requested help deals with the lost of memory of the patient. In his opinion, the relatives would have to receive practical training through the attendance to focus groups, conferences, etc.

Three Psychologists were also interviewed, one from each participating city, who agreed that the help must be offered to relatives is more relevant at the beginning of the illness, just after the diagnosis, as this is the moment where the relatives feel very lost. The most difficult task usually is to make relatives understand and accept the new role they have to acquire within the family environment and to face the new challenges. That is why the family usually request information about the development of the illness and the future consequences, as they feel afraid of further deterioration. In the opinion of all these professionals, the training offered to the relatives regarding specific problems, it should be completed with groups where they could talk about their experiences with other relatives, in order to exchange the problems the face everyday.

In the opinion of the Occupational therapist, the relatives have a big lack of information regarding the MS and how to deal with it. The most requested information by the relatives is, in his case, the way of facing the daily problems for common activities, for instance, having a shower, eating or dressing. In his opinion, it would be very useful for the relatives some practical training, subsidized by a public body.

Finally, 3 Social workers were interviewed, one in each city, who agreed that all of them have close contacts with the relatives of the people with MS, as one of their main roles was to intervene in the situations of the patient and the family. Usually, relatives have doubts and

questions regarding the following topics: available economical aids and grants for disabled people, how to obtain the right to home assistance, how to adapt the houses to the new technical requirements. In their opinion, the first months are very hard, and in this period is when they need to get clear information and available resources for them as well as psychological help.

5.2. Focus groups.

Taking into account the partners from Spain were four entities, three of them working directly with people suffering MS, they carried out three Focus Groups: one with people suffering MS in Bilbao and two with relatives of people with MS, one in Bilbao and other one in Madrid.

- Focus groups with the relatives.

Two Focus groups were carried out in Spain with relatives of people suffering MS: one in Bilbao and one in Madrid. The group organized in Bilbao had 7 participants, and the one held in Madrid 6, with different relations (partner, mother / father, brother / sister, son /daughter).

When speaking about the influence the illness had on their family life, all of them said that it had strongly influenced, changing the family roles, carrying out reparations and adaptations at home and feeling limits to their leisure activities. It is very hard for the family, mostly when it is a young couple. The labour situation had changed for some of them, depending on the development extent of the illness, the age and the gender.

As far as the cares given the patients, they had to help them almost in every daily task, such as hygiene, getting dressed, eating, as they cannot manage by themselves.

When they were asked whether they have ever received any training concerning MS illness and how to take care of these patients, most of them said that the only source had been the professionals of the day centre (doctors, neurologists, ...), from whom they received specific information according to their needs. Anyway, all of them agreed that it was not enough, as they would need integral information, not only concrete aspects, so the knowledge is usually acquired with the daily practice and they feel unprotected.

They find a lot of difficulties when caring the patients, mostly technical and psychological difficulties, how to act in specific moments when his / her spirits are very low, for example. Moreover, all of them feel that they do not have a "normal" life apart from the care giver roles, and

they need to have rest and to “switch off”, having some leisure time for themselves. Moreover, when the houses are not adapted to the technical needs they have a lot of difficulties for the daily tasks (shower, bed, etc.).

The possible solutions, in their opinion, would be to receive basic training at the beginning of the illness process, mostly being acquainted on general topics and the development of the illness. Then, after some time, they would need more specific information, such as how to do the transferences or the movements of the patients. Moreover, it could be very helpful to hold periodical groups for the exchange of personal experiences with other relatives of people suffering MS. Finally, the fact of having training materials based on ICTs would be helpful for them, as they could use them at home in their own time.

- Focus group with the people suffering MS.

One Focus Group was organized with people suffering MS, in order to know their opinion about the training lacks their relatives might have when taking care of them. It was held in Bilbao, with 6 participants.

Concerning the daily activities of them and their relatives, all of them agreed that they had changed a lot, mostly for those relatives whose patients live with them. They were aware of the fact that relatives had had to leave their jobs, in some cases, and their leisure activities in their free time for taking care of them. This way, patients whose illness was not at very serious level, preferred to ask for help from the outside, since they did not want to be a burden for the family, but always with economical help from public bodies or institutions.

Most of the relatives had acquired knowledge on MS very slowly, with the practice, and according to the current needs of the patients. In this group there were also some of them who had received training on MS care aspects specifically, and so they were able to apply these skills to the patients. But in general, they see that relatives do not feel sure for carrying out certain tasks, mostly the ones dealing with movements or transferences.

The big problem was that most of their relatives did not have time or receiving training in a classroom or in the MS Association or Day Centre. And the possible solutions for these problems could be the professional assistance, but organizing it in a comfortable way, it means with no time or space limits, as this is mostly their major problem. The training should be very practical, with a lot of videos, pictures and real cases.

6. CONCLUSIONS

We can summarize the contributions of our participants in the following points:

- Most of the relatives find difficulties in their daily tasks for taking care of persons with MS, as their knowledge on the illness has been acquired day-by-day, with the practice and without formal learning in most cases.

- Their major needs would be psychological support in order to know how to handle the difficult situations and guidelines for the transferences and movements of the patients.

- Concerning the information they receive from the professionals, it is mostly at the beginning of the illness, after the diagnosis. But they said that they still need it after some time, as the illness can have different developments and they have to know to handle all the situations.

- As far as the training is concerned, all of them said that it was necessary, but they found the problem of availability, as they do not have time to attend lessons. So, one of the solutions could be training based on ICTs in order to use it at their own homes whenever they had free time.