

THE SOCIAL PROTECTION SYSTEM IN RESPONSE TO MULTIPLE SCLEROSIS IN SPAIN. CASE STUDY OF ALICANTE

PhD. Assistant Professor María Carmen Pérez Belda

Department of Social Work and Social Services.
University of Alicante.

Address: Carretera San Vicente del Raspeig s/n.
03690. San Vicente del Raspeig, Alicante. Spain.
Telephone +34 965 3400. 2173
E-mail MC.Perez@ua.es

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Abstract

An increase in the attention given to the experiences around care work is taking place in the academic world due to consequences in the economy and public sector, the aging process of our societies, the new family trends and the global crisis. This article explores women struggles in long-term care with Multiple Sclerosis (MS) in Spain, in the province of Alicante. It focuses on the provision of care and the availability of services. In order to promote good practices in MS cases it is important to understand and explore the difficulties and experiences of affected people and their caregivers before and after the approval of the Law 39/2006 to promote the autonomy of persons in a dependence situation. The needs of the interviewed cases are described in a six year gap. The difficulties in the implementation of the law come because of delaying time periods of resolutions and real accessibility to services in this study.

Keywords: Long-term care, multiple sclerosis, social protection system, caregivers.

Introduction

In Spain a restructuration in the management of care responsibilities has been taking place in the last few years. Long-term care has been extensively studied in recent years before and after the adoption of the Law 39/2006 to Promote the Autonomy of Persons in a Situation of Dependence, because this normative suppose the assistance as a subjective right (Massanet and La Parra, 2009; Martínez Buján, 2010; Agrela, 2010). The relevance of this study belongs to the analysis of the implementation of the latest normative in a multiple case study and in the promotion of good practices in the province of Alicante, which is not statistically representative, but shows the main difficulties that families with Multiple Sclerosis still find in accessing services and benefits. This becomes even more important in the economical crisis period that we are living in.

Before the approval of this latest normative, the services offered were means tested with an assistance character, a low extension, and intensity in addition to the lack of coordination. (Rodríguez Cabrero 2004, 241-245). Social Services were: *Help at home*, its purpose is to offer personal, psychosocial, educative domestic and technical attention in their own home to promote autonomy and to avoid institutionalization. *Centres of orientation, diagnosis and treatment*, where a technical assessment of the disability and the right for economical allowance or pension is emitted. *Day centres*, many of them managed by private enterprises which have agreements with the public administration. *Residences*, public and private: The public administration offered grants to pay part of the private ones. *Tele-care*: a technological aid for a contact social centre in a situation of need. Finally there is also specific *emergency help* for crisis situations. (Mira-Perceval Pastor et. al 2007, 337-380).

Social Security offers different benefits for health assistance, temporary or permanent disability, invalidity and economic benefits of caring for a child younger than 18 years old or older than 18 but with a 65% disability level or higher. Besides that, there is a non-contributory pension system financed by the Central Administration for people who do not qualify for the benefits of the contributory system and without family support.

The innovation with the new law 39/2006, comes with the universal character for all citizens on the availability services as a subjective right. The services and benefits are provided in relation to the grade of dependency, being classified into three levels (moderate, severe and big dependence), and these are mainly the same services than before the law. The economic allowances are linked to contracted services from private sector when public services would not provide it. An economical compensation for caregivers in the family environment will be offered only in exceptional cases, with the affiliation of the caregiver to Social Security. Finally, fiscal benefits would be obtained for people who contract private insurance. But to understand the implementation of this law, it is necessary to clarify that according to the current Constitution (1978), Spain is organized territorially into 17 Autonomous Communities, Provinces and Municipalities. Alicante is one of the provinces of the Valencian Autonomous Community. Each Autonomous Community has its own government and adopts its

own policies, although following national policy guidelines. Regarding the state law 39/2006 to promote the autonomy of persons in a situation of dependence, the implementation belongs to autonomous community governments.

The object of study in this research is the full extent that the law means for people with multiple sclerosis and their families, paying special attention to the real availability and consequently the main providers of care. Thus, the goal of the research is to analyze if the social protection system responds to the needs of people with Multiple Sclerosis in Spain and specifically in the province of Alicante, looking at the differences before and after the new law to promote their autonomy. According to the research object, the following problem questions are formulated: What is the role of informal care before and after the latest normative? And, what are the main differences in the provision of care after the latest normative?

Partly from the bibliographical review, the empirical data of this article is based on a multiple case study with three women interviewed in the province of Alicante and it is part of broader research work for a doctoral study. The interviews were done individually, tape recordings and in two different moments with a gap of six years, before and after the approval of the law to promote the autonomy of persons in a dependence situation, in the years 2005 and 2011. The help of MS associations and peer groups was essential to find the cases and establish the first contact. The content analysis (Flick, 2004) is based on the next categories: a) formal care, b) informal care, c) main changes, and d) main caregiver. In this article, in order to preserve the anonymity of participants, the cases are numbered from 1 to 3.

Recent studies pointed out the delay in the processing of applications of persons in a situation of dependence to obtain response and services. Besides that, the allowance for caregivers, which are supposed to be used in exceptional cases, become the most used. In addition, the inequalities between some autonomous communities and others, even between some municipalities and others (CERMI 2011, Barriga et al. 2009 and Bayarri i Catalán, and Fillat Delgado 2011) are remarked. However, to talk about social protection system for persons with Multiple Sclerosis (MS), first it is important to clarify what it means to have MS. This is a life-long, chronic and unpredictable disease of the central nervous system, based on an inflammatory demyelization condition. People affected and their caregivers live with it for decades. (Arbinaga, 2003; Rivera Navarro, et. 2009). This disease affects young adults, having a long duration and a gradual development of disability leading to a wide range of physical, social and psychological problems (Casetta, et. 2009). The most common symptoms: visual problems, balance and co-ordination problems, spasticity, altered sensation, pain, abnormal speech, fatigue, bladder and bowel problems, sexual and intimacy, sensitivity to heat and cognitive and emotional disturbances. The quality of life of people with MS is based on the fact of having equal rights and access to treatment, therapies and services in the management of MS, following the Code of Good Practices in Multiple Sclerosis (2008) or previous studies as Mitchel et. al (2005). Some studies remark the difficulties in the access of services and economic difficulties Plfeger (2009), Lohne et. at (2011) and the impact on caregivers (Borgosian et. al 2009 and Rivera Navarro, 2009).

1. Informal care still protagonist

The important role that informal care plays among the case studies is visible in all the cases. Before the approval of the law 39/2006 the means-test character prevented these couples from getting support and families then have the obligation to care for their dependents. Coinciding with Rodríguez Cabrero (2004) the extension and intensity was low in long-term care. During the first interviews any of the women with MS received services or benefits from the social services and their mothers were their main caregivers, with the exception of case 2, with the husband as the main caregiver, although remarking that in the future it could be done by a hired woman. This coincides with the feminization of care work in Spain (Massanet y La Parra, 2009; Agrela, 2010)

“A woman yes, well eh... if it arrives the day that I would be in bed or in a wheelchair, that you need more things, so... my husband until now is a ... until now he help me a lot, but if I need more, a woman. I would feel more comfortable (2).

As a consequence, families search for strategies to confront the caring situation. For example, in the case (1), the woman divorced in order to be eligible for any service or support. Because of the means-tested requirement her ex-husband registered in another town, (their son's home), although in reality they lived together in the same house. That woman received a disability pension since she was working before being diagnosed with MS.

“We just got divorced two months ago but we are living together here. – But now it is because of the benefits. Because if I wanted to adapt the bathroom, the benefits did not come because of the salary of my husband. What happens to most of people. Like the home service, they denied me because of that, so I say to myself, Ok I have to separate or to divorce. Because otherwise... he has to inscribe in other city, to do things well, to show that he is not living here anymore. So he has done it in the town where my son lives. Although maybe, anyway, they denied me because they consider that pension like mine of 800€ is enough. But it was the reason to get divorced.” (1)

This case shows how the family tried to find strategies to get services from public administration when these were not available and the caring needs were not covered. Previous studies reported also the difficulties to obtain services (Rivera Navarro et. al 2009; Pflieger et al. 2010).

Six years after the approval of this law, none of the cases received any formal support from the administration as a consequence of the new normative. This fact shows that even if this law should mean a subjective right for a person in a situation of dependence, in this study it is not happening, coinciding with recent results (Barriga et al. 2009 and Bayarri i Catalán, and Fillat Delgado 2011). The big differences not only between regions, even between municipalities, suppose among the case studies a delay in the application process.

Thus, informal care is still playing a very important role in this study. The effort of families is necessary when services are not well implemented and available. The dependence situation or chronic disease in the case studies means additional expenses in

daily life, for example in home conversion, and before and after the approval. This fact supposed for these affected women with MS and their families struggle in the economy of the family. All costs derived from the long-term care situation were covered by the family. According to Pflieger et al. (2010, 125-126) a general agreement exists on the negative impact of MS on the patient's income and patient development, especially female patients who less often received disability pensions. In addition, coinciding with Lohne et. al (2011), the sudden and unexpected attacks that a person can suffer, can make it difficult to obtain services, benefits and assistive devices. Following, the principles to promote quality life (MSFI), the importance of offering flexible timetables for caregivers in their jobs is very important. Rivera Navarro et. (2009) also remark its importance since working life means social nets which could help the caregiver and prevent from getting burned. Because as Mitchel et. al (2005) pointed out, to care for a person goes further than physical or sanitarian health, it means also participation, well-being and quality of life of affected people with MS but also of caregivers.

2. Does something change in care provision after six years?

The changes in the care provision of these case studies, before and after the Law 39/2006, comes in relation to the increase of dependence and the increase of economic problems to cover the needs due to the difficult access to available services. The cases have to arrange the provision of care of these women with MS among their families. Because none of them got after six years any service of benefit since the approval of the law, waiting for the final answer from the administration, what coincides with recent studies (Bayarri i Catalán, and Fillat Delgado 2011).

The differences in the "burnout" of the case studies and the quality of life of the affected women and their relatives come in relation to the economic family situation. Coinciding with Borgosian et. al (2009, 876), the detrimental impact upon the carer's career and employment opportunities, reporting the turn down job opportunities, change from full-to part-time employment, and retire. In case 1, the ill woman got a better pension which permitted her to hire an immigrant woman to care for her, outside of the legal system. In case 2, the woman did not perceive any pension or support from social services; she was a housewife and did not work in the labour market since she was married. The husband perceived a heritage that permitted him to buy a new adapted house to his wife's needs and to pay a woman for the household, while he cared for her in the most personal needs.

"My husband who has in his home town, land from his father, heritage of houses and so, he has sell part of it to build me a new house, first floor, adapted, where I could walk, and everything better for me, to eliminate any architectonic barrier and without any public help" (2)

However, in case 3, the couple, after buying a new house with lift, lost it because they couldn't pay for it anymore, being her mother was the main caregiver before and after the law.

“I was living in a fifth floor without elevator and ok, I was happy with that, but I bought this flat because to go upstairs until 5^o was... I mean that I didn't go out for not having to go upstairs again, so, finally we bought this with elevator. But yeahh, economically we go very bad because we pay double than in the other, after that a better car, you spend a lot of money, and in the association with the physiotherapist, for this, for that... and the money is the worst thing we are dealing with, or what I deal with” (3)

In general terms, feminization of care responsibilities is observed in this study along the last six years. The lack of support, despite the supposed subjectivity right that should mean the law, moves people to find strategies in care provision and the economic situation becomes a key factor that women demand when rights are not a reality, influencing the promotion of good practices for people with Multiple Sclerosis.

CONCLUSION

In Spain a restructuration in the management of care responsibilities has been taking place in the last few years after the adoption of the Law 39/2006 to Promote the Autonomy of Persons in a Situation of Dependence. Before this normative, the means-tested character in the access to services prevented the cases with MS from getting some support. Five years later, all cases were waiting for a positive response in the application process. It shows that the implementation of this law, which depends on social services in regional competition (which means disparities between regions), is very slow, which makes the availability of services difficult (Barriga et. Al 2009 and Bayari et. Al 2011).

In conclusion, the family plays an important role in the provision of care, especially women. Even if the new normative try to guarantee care as a subjective right is observable in the case studies, the important role of families, the feminization of care and the delay in the timing process get support. Although it is necessary to remark the importance of having this law as a legal national frame under which the implementation needs to be improved.

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ISPANIJOS SOCIALINĖS APSAUGOS SISTEMOS ATSAKAS IŠSĖTINEI SKLEROZEI: ALICANTES ATVEJO ANALIZĖ

Doc. dr. María Carmen Pérez Belda

Alikantės universitetas, Ispanija

Santrauka

Dėl ekonomikos ir viešojo sektoriaus raidos iššūkių, gyventojų senėjimo, naujų šeimos raidos tendencijų bei pasaulinės krizės akademinėje bendruomenėje yra išaugęs dėmesys socialinio darbo patirčiai. Siekiant skatinti asmenų, sergančių išsėtine skleroze, gerosios patirties sklaidą, ilgalaikės priežiūros atvejais svarbu suprasti ir ištirti problemas, su kuriomis susiduria asmenys, sergantys išsėtine skleroze, ir juos slaugantys žmonės, bei jų patirtį. Šio straipsnio tyrimo objektas yra įstatymo 39/2006 Dėl priklausomų asmenų autonomiškumo užtikrinimo prasmė žmonėms, sergantiems išsėtine skleroze, ir jų šeimos nariams, ypatingą dėmesį skiriant realiam paslaugų prienamumui ir pagrindiniam priežiūros teikėjui. Tyrimo tikslas yra atskleisti, kaip socialinės apsaugos sistema atliepia asmenų, sergančių išsėtine skleroze, poreikius Ispanijoje ir konkrečiai Alikantės provincijoje. Taikomas kokybinis tyrimo metodas – pakartotinis tikslinės grupės atstovų interviu su šešerių metų intervalu (2005 ir 2011 m.), t. y. kaip užtikrinamas priklausomų asmenų autonomiškumas prieš priimant įstatymą ir jį priėmus. Apklausiamos trys moterys, sergančios išsėtine skleroze, gyvenančios Alikantės provincijoje. Tyrimas nepretenduoja į reprezentatyvumą, tačiau jis aktualus tuo, kad atliekama naujausių norminių aktų poveikio analizė, atskleidžiamos paslaugų ir išmokų prieinamumo problemos, su kuriomis vis dar susiduria šeimos slaugydamos asmenis, sergančius išsėtine skleroze.

Šis tyrimas atskleidė, jog iki įstatymo priėmimo (pirmojo interviu 2005 m. metu) galiojusi norminė bazė neleido tiriamais atvejais asmenims, sergantiems išsėtine skleroze, gauti tam tikrą paramą. Praėjus penkeriems metams, visais tiriamais atvejais asmenys vis dar laukė teigiamą atsakymą į paraiškas. Tai rodo, kad šio įstatymo įgyvendinimas, susijęs su socialinių paslaugų regionine konkurencija (tai reiškia skirtumus tarp regionų), yra labai lėtas, neužtikrina paslaugų prieinamumo. Nors esama norminė bazė siekia užtikrinti sergančiųjų išsėtine skleroze teisę į socialinę priežiūrą, atvejų tyrimai rodo, kad svarbūs išlieka tokie reiškiniai, kaip paramos teikėjai šeimoje, priežiūros feminizacija ir ilga sprendimų priėmimo dėl paramos teikimo proceso trukmė.

Reikšminiai žodžiai: ilgalaikė priežiūra, išsėtine skleroze, socialinės apsaugos sistema, slaugytojai.