

Main Changes Experienced by Husbands Involved in the Caring for their Wives with Multiple Sclerosis in Finland, Austria and Spain

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ABSTRACT. *This paper examines husbands' experiences with wives in the long-term care of the Multiple Sclerosis disease in Finland, Austria and Spain. Avoiding generalizations, this study focuses on the main changes after the diagnosis in all levels – personal, economic and professional – because to understand and reach equality in the care work it is necessary to open debate about men's practices in this area. In this research, three couples in each country in the regions of Lapland (Finland), Vorarlberg (Austria) and Alicante (Spain) were interviewed. To analyze the findings, a gender perspective is used with a particular attention to the influence of the contextual factors in each case. Comparing Finland with Austria and Spain, big differences emerged related to the economic changes. Changes in the social and sexual life were common in most cases.*

KEYWORDS: *long-term care, husbands, change, Multiple Sclerosis.*

RAKTAŽODŽIAI: *ilgalaikė slauga, vyrai, pokytis, išėtinė sklerozė.*

Introduction

This article seeks to provide a greater understanding of men's caring practices dealing with their wives in long-term care. By analyzing the struggles and experiences of men who have wives with Multiple Sclerosis, it contributes to the general understanding of the subjective illness experience. The article addresses the following questions: How do husbands experience the need for a long-term care of their wives? What are the main changes in men's caring participation in each country?

These questions arise at a moment of history when new social changes are likely to increase the pressure for men to participate in caring for their families. Fifteen years ago, Kaye and Applegate (1994, 219) predicted that “although

our understanding of the challenges and rewards in family care-giving for men remains grossly underdeveloped, evidence suggested that there may be more males engaged in helping other relatives than previously assumed.” Kramer (2002, 3-36) suggested that the number of male caregivers would increase across the life course because of the increased longevity of the populations. Therefore, it is necessary to understand better these trends to offer effective responses. According to Kramer, men in our society are often expected to be in control, confident and concerned more with thinking than feeling; they are supposed to be providers, rational, assertive, courageous, competitive, action-oriented, able to endure stress, bear pain and achieve goals. Thus, the care-giving experience presents them with significant challenges and detrimental impacts.

Currently, the levels of individualism are higher and lifestyles are more diverse. Giddens (2006, 135-163) notes that Europe experiences new challenges directly related to globalization. Globalization, in a broad way, must be seen more than the integration of economic activities because the competitiveness in global markets is essential to the future of Europe and to the survival of its social model. Within this social model, the changes in family structures and their diversity transform patterns of caring and make the involvement of men more evident. These trends that strongly influence caring and gender roles within the families must be explored with the view of social environment and health-care policies.

Background of the Husbands-Caregivers

Contextualization of the Case Studies

Lapland is the northern region of Finland. According to the classification of Esping-Andersen (1990; 1999), Finland belongs to the social-democratic group of welfare regimes. The Finnish welfare state is based on the combination of solidaristic ideas of growth and full employment and the minimization of family dependence. The system is financed by taxes characterized by the principle of universality. It favors the public provision of free services rather than cash transfers to ensure equality and homogeneity. However, during the last years about 10% of the generous benefits were reduced although in a very equitable manner across the board of welfare provision (Moreno 2004, 6-7). The Social Protection System in Finland is covered through the National Pension Insurance, the National Health Insurance and the Rehabilitation and Disease Prevention under Kela.¹ These services are delivered through the social services and the net of hospitals and health care centers. It is municipalities that arrange

1 www.kela.fi (Elämässä mukana – muutoksissa tukena) (The Social Insurance Institution of Finland) (15.02.2008).

the organization of social services and the provision of income support. In the social services for persons with Multiple Sclerosis as well as for other disabled people, a personal services plan is drawn to clarify the services and support required by both clients and their caregiver or relatives.² These services include personal assistance, transportation service, service accommodation, home conversion, social and health care rehabilitation, primary rehabilitation and assistive device services, the adaptation training and rehabilitation counseling, the rehabilitation allowance and the family caregivers allowance.

Vorarlberg is the Western province of Austria. Austria is a part of the continental welfare regime. It relies on a strategy of “paying off” for social problems by subsidizing the exit or non-entry from the labor market and the right to social security. This model is based on labor market agreements between employers and trade unions with respect to insurance arrangements to cover unemployment, sickness and old-age benefits while individuals outside the labor market are dependent on local public or private charity. “Marriage-related patriarchy” is still a fundamental part of social policy with women depending on a male breadwinner for both economic and social security although they provide unpaid care and reproductive work in the family. This arrangement tends to reinforce class stratification through its employment centeredness as well as the gender division in the family (Hammer and Österle 2003, 38-42). Thus, Austria is based on the universal *Social Insurance* and the *long-term care allowance*. All persons in need of a long-term care are covered (old people and people with mental, physical and psychiatric disabilities). A long-term care allowance is intended to cover additional care-related costs and, therefore, does not present an increase in income. It belongs to the group of universal social benefits. It is considered a lump sum towards the costs of the required care.

Spain has 17 autonomous communities, and Alicante is one of three provinces of the Valencia autonomous community. The Spanish welfare regime belongs to the Southern European group (Ferrera 2005); it combines both liberal and corporatist elements, and it is universal in the health and educational system. In Southern European welfare regimes, familiarism is heavily related to the unpaid female work. Moreover, the low state capacities have restrained innovation and reform in the field of social assistance; the delivery of means-tested benefits requires administrative competencies that have been slow to develop in Southern Europe. At the time that the interviews were made the services and benefits in the long-term care were still means-tested and mainly included home care, day centers, temporary stays in residential homes, residential homes, tele-care and financial aid to dependents and caregivers. “The Law 39/2006 of December 14 on Promotion of Personal Autonomy and Attention to People in a Dependence Situation” (*La Ley del 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia*) has made the rights of people in a dependence situation effective by creating a

2 www.stm.fi (Ministry of Social Affairs and Health) (4.07.2008).

National System for the Autonomy and Attention to Dependency, but this law was approved after the interviews had been made for this study.

Conceptualization of Care

Traditionally, in the family women care for dependent members, children, old and disabled individuals while men's duty is to participate in the labor market. Care has become particularly important taking into account the aging population and the increase of women in paid work. The future demand for care and the way families supply this care affect family life and men's practices within family. Therefore, it is impossible to change gender relations without opening up a debate about men's practices. Men are still in power and dominant positions in both the public and private life despite many changes and advances in gender equality (Hearn 2002, 384).

Before starting the conceptualization of care it is important to remember Martínez Román's (2002, 145) words about people with chronic diseases who have the right to a good quality of life and human development opportunities. It does not make sense to allocate important human and financial resources to avoid mortality if social policies do not support this large surviving population.

According to Zechner, care enables a specific care work that covers the needs for care, the responsibility of initiating and maintaining caring activities, necessary resources and time as well as mental and emotional work (Zechner 2007, 33). In the Multiple Sclerosis cases, a long-term care is crucial due to the idiosyncrasy of the disease. Stone (2001, 97) defines long-term care as a type of care that encompasses a broad range of assistance that people with chronic disabilities need for a prolonged period of time.

Multiple Sclerosis Disease

Multiple Sclerosis disease is a life-long and unpredictable disease of the central nervous system. Concretely, MS is an inflammatory demyelization condition. Myelin is a fatty material that insulates nerves, acting as the covering of an electric wire that allows the nerve to transmit its impulses rapidly. It can disable or divest the communication between the brain and other parts of the body, affecting the motor and sensorial functions and sometimes the cognitive functions. Various symptoms emerge due to the disruption in the ability of the nerves to conduct electrical impulses to and from the brain because of the demyelization. The sites where myelin is lost (plaques or lesions) appear as hardened (scar) areas. These scars appear at different times and in different areas of the brain and spinal cord. Because of the localization of the lesions, the symptoms vary significantly. The lesions show some predilection for certain

parts provoking weakness, paresthesias, alterations in the vision, ataxia, etc. (Fernández and Fernández 2004, 13-45).

Husbands-Caregivers

Studies on care from the gender perspective show the inequalities between of men and women's roles as caregivers in families. Although many of these studies were based on women, some research also focuses on men as caregivers. Kramer and Thompson's (2002, 24) review of men-caregivers notes that women are still more involved in caring that is considered the essence of womanhood and femininity. In addition, the informal care provided for the elderly and disabled often become the responsibility of women in their later adult years.

To focus on husbands-caregivers, it is necessary, first of all, to emphasize the importance of the relationship between a male caregiver and care recipient not only within the marriage but also with regard to sons, brothers or fathers. It is not possible to presume that in all cases, spouses or partners care about each other equally and with the ability or willingness to do so (Fink 2004, 7). Feelings of embarrassment or hostility often appear in the physically intimate tasks of caring. A personal care may cause problems for the caring relationships when touching, nakedness or contact with excreta are involved (Parker and Seymour 1998, 187).

To appreciate the structure of the setting of care-giving and the influential factors that shape men as caregivers, it is also necessary to pay attention to the way male caregivers "do care-giving" for their wives differently. The patterns of care are influenced by the life phase, employment demands, access to and interaction with secondary caregivers, willingness to put oneself on hold and the relationship with the care-recipient (Parker and Seymour 1998). Gersten and Gallagher (2002, 199-202) as well as Detinger and Clarkberg (2002, 873-874) point out the importance of marriage for men in caring. They note that the nature of the care-giving experience depends to a great degree on the nature of the relationship between a caregiver and care recipient, particularly the spouse. Positive relationship is very important to adequate informal care provision: husbands' proximity and commitment in emotionally tight-knit marriages enable them to provide better instrumental and emotional support than it is possible in emotionally distant marriages. Ciambone and Allen also specified the quality of marriage as a key factor for the care-giving: "...marital quality is a far more important indicator of spousal care-giving than spousal availability" (Ciambone and Allen 2002, 307). However, when a person with the MS disease is provided with a care it means caring for someone with unexpected relapses and remittance periods because of the idiosyncrasy of the illness. This care may continue for decades since deceased individuals' life expectancy is more than twenty five years. The disease can affect 15-55 year-old adults 60% of which are women (Fernández and Fernández 2000, 13-38).

Methods

Sample

The sample for this study was husbands caring for their wives with the MS disease who lived in Lapland, Finland, Vorarlberg, Austria, and Alicante, Spain. These countries were chosen as an object of this study because of their different welfare regimes and different social protection systems in the MS cases. The purpose of the study is to trace the differences in the available services in Finland, Austria and Spain and to analyze how they affect men caring for their wives. I have chosen the province of Lapland because I have lived and studied there for three and half years. The province of Vorarlberg in Austria was selected because of its academic relations to the University of Lapland. They made my research much easier and more efficient. Finally, I have chosen the province of Alicante because it was there that I received my B. A. in social work. Women with MS were chosen because it was easier to find adult men involved in the care for their wives.

Data collection

A semi-structured interview schedule was used. Three study cases were selected in each country, 18 interviews with men and women in total. I received the consent of participants with the help of the presidents of the local MS associations and their support groups. The pre-selected couples agreed to participate in individual interviews. They were asked to talk in detail about the following areas: the diagnosis and progress of the disease, their participation in care (personal care, household and emotional support), the feelings experienced throughout the process, their relationship with a partner, the formal and informal support received and the main changes perceived and experienced in their lives. Most interviews lasted for a minimum of two hours and all were taped and fully transcribed. The interviews in Finland and Austria were conducted with the translators' help. They were trained and informed about ethical attitudes and key questions in advance.

The interviews in Spain were conducted before the new "Law 39/2006 of December 14th on the Promotion of Personal Autonomy and Care for People in a Situation on Dependency" was approved. This study was not designed to get an overall representative sample of men-caregivers. The main purpose was to examine and describe men's experiences and changes in their lives affected by their long-term care situation. I will take into consideration changes in men's economic and work status, social life, marital relationship and intimate life. It should be mentioned, at the outset, that of the 9 interviewed husbands three were not caregivers, two of them were from Spain and one from Austria.

Results

Changes in Economic Situation

The changes in the families' economic situation as a consequence of the MS disease had enormous consequences in some cases. Two Spanish husbands had to buy new flats with elevators and the required home conversion for their wives with no help from the municipalities.

In Austria, no husbands or wives mentioned any change in their economic situation. Husbands continued their jobs and women received a disability allowance that in most cases was saved. Relatives, mainly women, provided care for them. Only one husband contracted an outside woman for a household and personal care.

In Finland, husbands took the responsibility of becoming the main caregivers for which they received a caregiver allowance. The municipality provided all necessary home conversion via individual plans. However, family income levels decreased because these husbands quit their jobs and the minimum caregiver allowance was only around 600 EUR. The men decided to become caregivers because of the unemployment situation in the region of Lapland at that time.

Changes in Social Life

In most cases, husbands' social life became less active. Austrian husbands noticed this change immediately. The men had to reduce their social life and to adapt to the new health condition of their wives. It also affected family friends and guests who experienced difficulties and discomfort in the face of the new situation.

All three Spanish husbands reported that their social life became less active. However, two men intended to continue to live their lives as they did before their wives' illness. Their inability to adapt to their wives' needs affected their marital relationship and made them think of a divorce. Instead of participating in the care of their wives, they left it to their daughters and the wives' mothers. The third Spanish man became the main caregiver of his wife. It should be mentioned that this family did not have any relatives living near by or any daughters, only two sons.

The Finnish husbands mentioned the change in their social life as one of the strongest experiences because they had become the main caregivers of their wives. They quit their jobs and focused on caring tasks. Even if someone from the municipality came to look after their wives, they felt that no one could take better care of their wives than they did.

Changes in Intimate Life

Most husbands also mentioned a decrease in sexual contact with their wives. However, not everyone was able to talk about it openly. The symptoms of MS that progressed differently in each individual case affected their marital relationships and the way the men handled caring and emotional nurturing. Yet every man dealt with it differently. Parker and Seymour noted difficulties in the sexual life of spouses-caregivers and care recipients related to the way that recipients perceived their bodies and changes that affected them (Parker and Seymour 1998, 187-191). However, in this study, the men experienced more problems because they could not adjust to the difficulties that they encountered while having sex with their wives.

All Spanish men were more open about changes in their sexual lives while the Finnish men found it more difficult to talk openly about it. Only one of the three men could do it. Only one of the Austrian men, the youngest one, showed more reticence talking about his intimate life. But all cases experienced a significant change in their intimate lives.

TABLE 1. RESULTS OF THE MAIN CHANGES IN THE HUSBANDS' LIVES AFTER THE DIAGNOSIS OF MS

	Finland	Austria	Spain
Working Status	Main caregivers with a family allowance. Three husbands cared for their wives	Need for work outside home. Two husbands cared for their wives	Need for work outside. Only one husband cared for his wife
Economic	No changes	No changes	Big changes because of the home conversion
Social life	Changes (very tired)	Changes (in going out and receiving visits)	Changes (in going out, did not adapt to dependency)
Sexual life	Difficulties in talking about it in two cases (independent/semi-dependent)	Difficulties in talking about it by the youngest husband Independent case	Reported and experienced by all husbands

The table summarizes the main changes in husbands' lives after their wives' MS diagnosis. Their social lives changed most significantly while the economic change affected the Spanish men most. This can be explained by different social security systems of three countries and different services offered by each system. The Finnish men had an opportunity to become the main caregivers and to receive an allowance for it. The Austrian and Spanish systems supported the traditional role of a male breadwinner, thus, caring for their

wives was an obligation. In Austria, it was compensated while in Spain it was not. All men's sexual lives have also changed. However, some men did not talk about it openly. Men with dependent wives discussed the changes more freely. Generally, the Spanish men were most open.

Discussion

The Link between the Social Security Systems and the Changes in the Husbands' Economic Status and Caring Responsibilities

In the Spanish and Austrian cases in which the social security system supported the traditional labor division between the public and private spheres (men-breadwinners and women-family and household caretakers), the interviewed men did not experience a significant change in their work status. They continued to work outside home. Thus, these husbands were less involved in the care for their wives than the Finnish men. The Finnish social security system supported the possibility for men to be involved in the care in a formal way through a caregiver's allowance. However, the minimum allowance amount was rather low (only around 600 EUR) and it might have made some men decide against becoming a caretaker. The interviewed Finnish husbands have chosen to become caretakers because of the high unemployment rate in the region. Even if the allowance was low, they had a choice. In countries such as Spain and Austria, the social security systems forced families to assume the responsibilities of care. The means-tested character of social services in Spain excludes many people from receiving it. In Austria, an universal allowance for the disabled people with freedom to spend it is supposed to cover the dependent person's needs but in many cases it is put into savings and the family takes care of a sick person. It should also be mentioned that even when a family organized and contracted help for the dependent person, it was always a woman from the labor market. The study shows that care was feminized both in Spain and Austria. The main difference between these countries was that in Austria the economic income of the family was not affected because of a long-term care while in Spain it changed the family's economic well-being (the family had to provide a disabled person with the care, in most of cases, without the support from the social security system).

It is possible to conclude that the social security systems directly influenced husbands' experiences in assuming or not assuming the responsibility of care. In Finland, they could choose to become caregivers and receive the allowance for it. In Austria, the social security system forced families to organize or contract the care from outside. The husbands continued to work and family members or hired persons, mostly women, looked after their wives. At the time

that the interviews were conducted the Spanish social security system forced families to assume the responsibility of caring with no support from it (with the exception of universal health services). The Spanish men continued to work while family members, largely women, became caretakers. It is evident that the social security systems influencing the changes in caring responsibilities and in the economic situation reproduced traditional gender roles in Austria and Spain (women as caretakers). They also affected the long-term care situation, the quality of life and sometimes the quality of care in the Spanish families. However, the social security system also offered a possibility of care in the case of Finland. The study demonstrates that the Finnish men became caregivers of their wives because of the unstable job market in Lapland at the time.

La Parra (2002, 34-88) argued that the process of gender construction, the organization of the labor market and the Welfare State influence the way a society organizes the informal response to care-giving needs. This study demonstrates that the social protection system is the main factor affecting the choice to become or not to become a caretaker.

The Link between the Good Previous Relationship and the Adjustment to the Changes in Social and Intimate Life

In analyzing the husbands' adjustment to the changes in their social and sexual lives after the diagnosis of MS for their wives, we should pay attention to the quality of the previous spousal relationships. Some authors argued that the marital status was a key factor for men to get involved in care (Parker and Seymour 1998). However, not all interviewed husbands participated in caring for their wives. Only the men with a good previous relationship seemed to be involved in caring and adjusted to the changes in their sexual and social lives. Detinger and Clarkberg also supported this finding. According to them, the care-giving experience depended to a great degree on the nature of the relationship between a caregiver and a care recipient (Detinger and Clarkberg 2002, 873-874).

The interviewed men accepted their declining social lives and even social isolation differently. Moreover, most husbands reported the lack of a confident person to whom they could talk and share their experiences throughout the process of the disease. Therefore, support groups and self-groups of MS are very important.

Conclusion

This study demonstrated that the diagnosis of the MS disease affected many aspects in the interviewed men's lives. It changed the patterns of intimacy, social life and economic well-being. The disease also presented the men with

different options and alternatives because of the different social security systems of three countries. In Finland in which the state took care of the disabled people the interviewed men participated in caring for their wives. However, their decision to become caregivers was related to the unstable labor market. In Austria and Spain, policies made a family the first provider of care. In Austria, it was achieved through a long-term care allowance. In Spain, the means-tested character of services in the long-term care forced a family to assume the responsibility of care without the economic and universal support available in Austria. In both cases, women were the main caregivers and husbands were less involved in caring than in Finland. It means that in addition to the economic change, the care in Spain and Austria was feminized. The research presented in this paper cannot fully capture the complexity of the husbands' experiences. However, it can contribute to a better understanding of the factors that either encourage men to participate in caring for their wives or discourage them from assuming this responsibility.

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Santrauka

Straipsnis analizuoja vyrų, ilgą laiką slaugančių žmonas, kurios serga išsėtine skleroze, patirtis Suomijoje, Austrijoje ir Ispanijoje. Vengiant apibendrinimų, studijoje koncentruojamasi ties pagrindiniais asmeniniais, ekonominiais ir profesiniais pokyčiais, įvykusiais po išsėtinės sklerozės diagnozės, nes siekiant suvokti ir įgyvendinti lygybę slaugos sferoje būtina diskutuoti vyrų patirtis ir praktikas šioje sferoje. Šiam tyrimo buvo atlikti interviu su trimis poromis iš kiekvienos šalies. Buvo apklaustos poros iš Laplandijos Suomijoje, Vorarlbergo Austrijoje ir Alikantės Ispanijoje regionų. Analizuojant interviu naudotasi lyčių studijų perspektyva, ypatingą dėmesį kreipiant į kiekvieno atvejo kontekstinius veiksnius. Lyginant Austriją ir Ispaniją, didžiausi pokyčiai vyrų gyvenime siejosi su ekonominiais faktoriais. Bendriausi visoms šalims buvo pokyčiai, įvykę socialiniame ir seksualiniame vyrų, slaugančių žmonas, kurios serga išsėtine skleroze, gyvenimuose.