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Aging populations, chronic diseases, gender and the risk of disability

Sally Bould Sara Falcão Casaca

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SOCIUS - Centro de Investigação em Sociologia Económica e das Organizações ISEG - Instituto Superior de Economia e Gestão Universidade Técnica de Lisboa R. Miguel Lupi, 20 1249-078 Lisboa Tel: 213951787 Fax: 213951783

E-mail: socius@iseg.utl.pt
URL: http://pascal.iseg.utl.pt/~socius/home.htm

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University of Delaware, USA and CEPS, Luxembourg,

Sara Falção Casaca

ISEG, School of Economics and Management, Technical University of Lisbon SOCIUS, Research Centre in Economic and Organizational Sociology

Introduction

The current discussion in the EU of the increase in life expectancy as it relates to pension reform misses a big part of the picture. The increase in life expectancy in Europe, as in the US, is accompanied by an increasing risk of disability in the later years. The time between the onset of a chronic disease and death has increased dramatically in the last half century. It has also created a situation where older workers risk being limited in the kind of paid work they can do and the very old risk having two or more chronic diseases. The high prevalence of chronic diseases and disabilities in aging populations has not yet been recognized by the new policy of "Live Longer Work Longer" (Keese, M. et al. 2006). How are workers to work longer if they are limited in the kind and type of work they perform? Official European Union documents stress the demographic changes in Europe primarily the increase in life expectancy but not the increase in disability.¹

Diversity of Ability

The assumption of EU reports that increasing "life expectancy means higher life expectancy in 'good health' and in the absence of disability" is only part of the picture. What is most striking, however, about the aging of the population is the diversity in health at older ages. Many individuals age well, while many others suffer from two or

¹eg. http://europa.eu/legislation_summaries/employment_and_social_policy/disability_and_old_age/c10160_fr.htm.

² eur-lex.europa.eu

more chronic diseases. Even at ages 55-64, some individuals are already limited in the kind of work that they do, although the majority is still free of a work disability. At ages 85 and over, one quarter of this very old population (28%) is reporting an ability to work without limitations and at the same time 24% are living in a nursing home (Bould, Smith and Longino, 1997) and an estimated 40% need the help of another person for activities of daily living. Aging policies must deal with both the well old and the disabled old. Among those 70 and over, the increase in life expectancy has been achieved at the cost of increasing the risk of chronic diseases and disabilities during the latter years of life (Crimmins and Beltran-Sanchez, 2011). A century ago life expectancy was shorter, but the years of disability were more limited, enabling the vast majority of older persons to be active until near death.

This increasing risk of chronic diseases and disabilities has gender dimensions. The first is that women aged 51-61 are more likely to be disabled than men at the same age as men. Evidence from the United States suggests that over 40% of women in these ages have strength limitations in comparison with about 20% of men (Wray and Blaum 2001). This gender difference, in part, reflects the role of chronic disease. Women in these ages are more likely to be disabled by musculoskeletal conditions whereas men at the same age are more likely to be disabled by cardiopulmonary conditions but overall it is women who are more at risk for disability than men among older workers. Gender neutral approaches for raising the retirement age ignore these important gender differences in chronic diseases as well as disabilities.

The EU policy on "active aging" not only overlooks those age 55-64 with disabilities related to work limitations, but also ignores the situation of persons over 65 who are at a high risk of disabilities in performing the activities of daily living, such as shopping, or even cooking. The older the person is, the more likely they are to be disabled, and women are more likely to be disabled at these ages than men (Wray and Baum, 2001). Furthermore, it is typically the daughters and the daughters in law who are needed to provide care for elders in their family who are disabled (Cf. Calasanti, 2003). If the daughters are now expected to work, who will care for the aged parents?

Disability and Chronic Diseases

In order to understand the situation of disabled persons, it is important to develop a detailed understanding of the role of the chronic diseases which cause disability at these ages. In the EU discussion of health appears limited in understanding this. In the Decision No 1350/2007/EC of the European Parliament and of the Council of 23 October 2007 establishing a second programme of Community action in the field of health (2008-13) notes that the majority of diseases are chronic, but in listing the key diseases, there is no mention of Alzheimer's disease and dementia (these are covered only in a special report focused only on these diseases; see below). Similarly musculoskeletal diseases are not mentioned; these latter diseases are likely to disable women at older ages, and the most common cause of a mobility disability of all persons 65-84 (Wray and Blaum, 2001).

In another section of this document the discussion of morbidity is analyzed together with mortality and so musculoskeletal diseases are far down the list, and Alzheimer's is not even mentioned. Since some diseases are less likely to disable and more likely to kill (e.g. cancer) while other diseases are more likely to disable and less likely to kill (musculoskeletal diseases) this combined picture of morbidity and mortality provides a misleading approach. Disabling chronic diseases must be analyzed separately from chronic diseases which are likely to result in death without a lengthy time of disability. In addition women are more likely to get the latter type of chronic diseases where as men are more likely to get the former. If there is to be effective Community action in the field of health it is necessary to understand an essential dichotomy between chronic diseases which are more likely to result in disability and chronic diseases which are more likely to result in mortality as well as important gender differences in these non communicable diseases. The measure of Disability Adjusted Life-years (DALY) used in these documents obscures the understanding of disability as distinct from mortality.

The gender neutral approach of expecting women as well as men to be in paid work during the years from 55-64 also overlooks the possible need for their carework (Arber, Davidson and Ginn, 2003). At these ages the parent generation is at high risk of

being disabled and needing care. Again this is a consequence of the higher risk of chronic diseases and the consequent disability which accompanies the longer life expectancy. For women aged 70 and older, half are facing mobility difficulties (Wray and Blaum 2001). In understanding disability at these ages, however, it is no longer the question of work limitations, but rather the need for the help of another person in order to perform the activities of daily living which require mobility. Furthermore without help, an elderly person with mobility difficulties is at increased risk of falling. And falling, for a women with osteoporosis can result in an inability to get out of bed, or even a permanent move to a nursing home.

A Disability Strategy for Persons over 65?

Not only do EU documents on health overlook the role of chronic diseases that disable at older ages, but the EU documents on disability appear to focus primarily on persons of working age, that is under age 65. The European Disability Strategy 2010-2020³ involves an objective of data collection to examine the situation of disabled persons and the labour market. There is no mention of the effect of a disabled parent on the labour market participation of the older women worker. And there is no mention of the role of chronic disease in causing the disability. Instead the Strategy is focused on "Building a barrierfree Europe" by focusing on accessibility, transport, and information. But this focus on access and transport is not always applicable to disabled elderly persons, because what they need is "paratransit"; that is a system of special vehicles with a person to help them on and off. For those over age 70 who have a mobility disability (more than one third of the men and half of the women) they often need more than accessibility or a device, they need the help of a person. And the older the person is the less likely that they can manage with only a device. Of course, many of these individuals will benefit from providing wheel chair access for all, but the majority of them, and especially among the very old need the help of a person to get in and out of the wheelchair.

There is always the option of paying a person to help with transport, or for the more able, hiring a taxi. But these options are costly. he increase in life expectancy has

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³ http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=SEC:2010:1324:FIN:EN:PDF

resulted in more and more elderly persons in or near poverty living to these very old ages where the risk of disability is high. In Spain, a relatively poor country, life expectancy is greater than in the Netherlands or Germany. And it is women who live longer, and have a higher risk of disability during the last years of their life. These demographic changes have created a large population of very old persons, disproportionately female, who are in need of in-home care by a person. Most of these elderly persons cannot afford to pay for this care (Bould, 1997).

An example of the crisis of care is found in the predicted doubling of older persons suffering from Alzheimer's disease in Europe between 2009 and 2029. This special report on Alzheimer's disease and dementias also notes that these diseases are "the forth leading cause of burden of disease in high income countries." (Commission Staff Working Document, 2009). These diseases require long term care and the burden is largely on families, which means women in most EU countries. Furthermore this disease is not one that can be managed by a family member dropping by a couple of times a week after work. Alzheimer's generally requires a live-in caregiver. Thus far, increasing life expectancy has greatly increased the risk of Alzheimer's so many adult daughters and daughters-in law will have full time caregiving responsibilities. In some cultures daughters will take the responsibility for care of their mother (or mother-in-law) even if their father (or father in-law) is present and able to provide care.

The concept of "active aging" has been linked with productive activity; this activity is usually defined as paid work. Women's unpaid work has not even been considered "productive" activity although changes have been proposed by the ILO (Cf. Bould and Gavray, 2009). It often ignores that much of the work that older women do is unpaid and "off the books". According to Picchio (2010: 74) the woman's "problem is not having too little but too much work to do. To take account of this and avoid mistakes in analyses and policies, one must adopt a different perspective and begin to reason in terms of total labour, paid and unpaid..." Although social policy has moved over the past four decades to take into account "reproductive work" and work-family issues of mothers, older women as caregivers for the very old are often invisible (Krekula 2007; Lewis 2009; Vincent, 2000).

Policies for aging populations need to focus on the unpaid labour of caregiving which becomes essential when there is a high risk of disability as persons reach very old ages. The EU directives on providing for persons with disabilities seems to ignore the simple fact that an increase in the risk of chronic disease increases the risk of needing care and it is families who provide the vast majority of that care. The EU disability strategy encourages states to take "measures to allow persons with disabilities, as far as possible, to live independently, to be included in the community, and to have access to quality care and support services". But outside the Nordic countries there are limited support services available for the disabled elderly person, especially to live "independently" in the community. Furthermore, the EU discussions of the rights of the disabled appear to be focused on access and devices. Such approaches are useful for younger persons who have a disability, but the older the disabled person is, the less likely that they will be able to manage with only a device. Forty year old's can manage to live independently with only a cane but 80 year olds who need a cane to walk, are also likely to need a person to accompany them outside of the house. Furthermore a significant majority of disabled elderly persons would prefer to be cared for by their families, and this usually means their daughters or daughters in law. Up until the proposed and recent changes, women aged 55-64 could perform the needed caregiving work and, if they have worked, be eligible to receive a pension. New policies of budget cutbacks are limiting the income sources for these women, not only retirement benefits, but also pre-retirement benefits, disability and unemployment benefits.

Different Welfare Regimes

The issue of older women working vs. caring has very different dimensions depending on the type of welfare régime. These issues raise directly the problem of who will care for the chronically ill and disabled older population? Some welfare regimes attempt to provide the necessary conditions for *defamiliarisation* (McLaughlin and Glendinning 1994 cited in Mahon, 1998: 158). Jane Lewis (1992) states that when non-paid work dimensions are added to paid work ones, it is then possible to identify some variations of Welfare States. Birgitt Pfau-Effinger (1999) has also incorporated the importance of gender ideologies; each welfare state regime has embedded the dominant ideologies with

regard to women's and men's roles in society and this shapes the way how public policies are defined and social facilities are implemented (Lewis, 1992; Orloff, 1993). It is not surprising, then, that the pattern of older women working (See Figure1 – appendix) appears to be impacted by attitudes concerning family care of the elderly person as well as how the state itself provides supports for this care.

In the Mediterranean countries of Spain, Italy and Greece older women's employment rate is below one third. These countries have a familistic approach (Ferrera 1996; Trifiletti 1999) in which a woman's first priority is care of her family (Lewis, 1992); men's primary responsibility is as the main breadwinner and women's is as the home care provider (Pfau-Effinger, 1999). Consistent with this gender ideology is the very large differences between older women's employment rates and older men's rates, more than 20 percentage points and in the case of Spain and Greece over 30 points in the case of Italy (Eurostat)⁴. Historically these countries have also provided earlier retirement for women than for men. The limited employment of older women is linked to the expectation that these women are responsible for care for elderly family members in need. Over 85% of the population surveyed in Italy and Greece sees the family as the principal provider of care for elderly family members (Sundstrom et al. 2008: 250). In Greece, Italy and Spain the family has a legal obligation to provide care for its elderly members. Elder care in these countries is also provided in three generation households. The low level of employment for older women is congruent with the cultural expectations as well as the legal requirements. If women continue to work in these countries, the serious question is who will provide the care as public services in this area are limited (Gibson, 1996; Krekula, 2007).

While Portugal has often been classified together with the Mediterranean countries (Cf. Ferrera 1996), Portuguese women have had a long tradition of employment, especially in the primary ages 25-54. Women in these ages have an employment rate over 70%, equivalent to the employment rate of women in Belgium (Figure 1, appendix). This is surprising because the availability of publicly supported child care in Belgium is high and in Portugal it is lower. The explanation is found in the much lower employment rates of older women in Portugal; in many situations, the

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⁴ Eurostat website, labour force survey: annual series. extraction: 23/08/2010.

Portuguese grandmothers are still expected to provide much of the childcare. Portugal shares many characteristics with the Mediterranean countries in terms of the welfare state features, gender ideologies and family characteristics (Casaca and Damião, 2010) but the cultural expectation in Portugal is for prime age women (aged 25-54) to work full time but for older women (aged 55-64) to be retired and able to care for elderly family members and grandchildren.

In Denmark, Sweden, Finland and Norway women aged 55-64 have high rates of employment, 50% or more (See Figure I, appendix). In this cluster there is an explicit family policy with the state having the final responsibility for the care of elderly persons. There is no legal family obligation to care; each municipality provides for the care and financing for its elderly residents who need help (Cf. Sundstrom et al, 2008). According to Birgit Pfau-Effinger (1999), the dominant gender model is based on the idea of a fulltime integration of men and women into the employment system, and the State has for long been committed to this principle. These countries have adapted to the increasing life expectancy with extensive social services for elderly persons with disabilities. These supports permit women to work to older ages, knowing that their parents will be adequately cared for while they are on the job. Sweden and Norway have had these high employment rates for both older women and men for more than a decade; they have also provided very high rates of community services for the elderly (Cf. Lowenstein, Katz and Gur-Yaish (2008). In Denmark and Finland these high employment rates for older women are more recent; both Denmark and Finland also provide a high level of community services for the elderly.

Although attitudes in Sweden, for example, promote the state as responsible for elder care, this does not mean that the family is not contributing (Sundstrom *et al.*, 2008). Welfare states "do not crowd out family care" (Thane, 2010: 119). In fact, state support enables older women to continue working. In Sweden, women over age 50 who are caregivers report a 30% employment rate and in Denmark 25%; these rates are higher than in any of the other EU countries studied (Sundstrom et al. 2010, p 244). In addition, women's carework is also supported by opportunities for well paying, secure part-time jobs. In the Nordic countries part-time work can provide adequate wages and security. In Norway 49%, Sweden 43% and Denmark 37% of older women work part time and 80%

of this part time work is voluntary in these countries. In the Nordic countries employed older women are more likely to report choosing voluntary part time work due to family and personal responsibilities. In addition women in these countries can often count on men to help provide care, especially elderly men caring for their disabled elderly wives. The experience of Finland illustrates the problem for many women in policies to retire at later ages. The explicit policy of using pension incentives to encourage working longer into older ages was not attractive to older Finish women. The problem was that the women needed to retire earlier because of the "need to help others". A new program of part time pensions and retiring from full time work was developed to give women a choice; a survey found that "38% of part time pensioners, especially women, were involved in care activities related to their family members, most typically a spouse parent or grandchild." (Kauppinen, 2010). The rapid increase in the employment rate of older women in Finland is linked to the ability of older women to combine work and care with the special policy of combining part time work with partial pension payments. The Nordic countries, as well as The Netherlands are ahead of the rest of Europe in that the retirement age had already been increased to age 65 or more and the rates of employment are high for both older women and older men. These countries all provide for state supported services for the elderly and support for adequate part-time employment.

The rest of Europe, often described as Northern Europe i.e. not Southern nor Nordic (e.g. Sundstrom et al. 2008) has a mixture of family and state responsibility for the elderly; only 12 % of respondents in the UK and 11% of the respondents in Germany report that care for the elderly is mainly a state responsibility where the family contributes. Patterns of employment for older women in 2009 vary from a low of 27.7% in Belgium to a high of 49.2% in the UK. While there are a great many factors which impact this behavior in each country, the liberal welfare state of the UK and also of Ireland can be distinguished from the continental welfare states (Epsing-Anderson, 1990). "In Britain, official policy continued, as it had done since the 1950s and for long before, to assume that formal services were ancillary and complementary to those of the family" (Thane, 2010: 119). The tradition is to provide services for the elderly who are poor. The family, with its access to the market, is responsible for the care of the majority of elderly persons.

All of the welfare states of Northwestern Europe, however, have provided unemployment benefits or other special benefits for older workers who are too young for full pension benefits and out of work. This system has provided support for older women with work histories who cannot find work, have work limitations, or need to care for an elderly family member. The impact of raising the retirement age in these countries will vary depending on the extent to which these benefits will be sustained even with the increase of the retirement age. Even before the current fiscal crisis, however, these benefits were minimal in many welfare states. The findings from SHARE (Survey of Health, Aging and Retirement in Europe) indicate that income from unemployment benefits and disability benefits for those over the age of 50 are already judged to be inadequate by the beneficiaries (Litwin and Sapir 2009).

Education

Education is the one measure of social class available in the Eurostat data. At all ages past 50, low education is linked with higher rates of disability. But it is also true that older workers with low education are likely to have parents who are still alive, but disabled. In understanding the vulnerability of women with low education (ISCED 0-2) it is necessary to examine the whole of Western Europe. Women with low education are less likely to work at every age except before age 25 (Bould and Gavray, 2009). The difference in the employment rate between highly educated (ISCED 5-6) and poorly educated women is even greater at older ages. For example, in Spain older women (aged 55-64) with low education have an employment rate of 25.0% in contrast to 61.8% for those with a high education in 2009. Even with the excellent retirement benefits in France, half of older women with high education were working in 2009 (50.1%) in contrast to 29.8% of those with low education. Educated women are more likely to be in better health and to have jobs which do not require physical strength. Women in the educated class, however, are more likely to have living parents since social class is so closely related to life expectancy; but either they or their parents will usually have the economic resources to hire home care. In the United States where adult children have a high imputed wage, the disabled elderly family member is more likely have hired home care than care provided informally by an adult child (Johnson, 2008). Policies to increase

the retirement age for women, then, can result in an extra hardship for women with low education. Women with low levels of education are typically from families which may need their hands on care for their disabled elderly members.

Current Policies

Finland's new options of providing part time work together with partial pensions appears to have been effective in providing secure opportunities for older women to combine work and caregiving. Part time employment has been the solution to combining work and care in the Netherlands and the Nordic countries. In a survey in Denmark and Sweden a significant minority of persons 50 and over who provided care also worked (Sundstrom et al., 2008). Thus it appears as if part time work could be a model policy for increasing older women's employment but ensuring that they have time for family. The situation in the Mediterranean countries and Portugal, however, is one where the majority of older women working part time are doing so because they are unable to find full time work; only a small minority work part-time because of family responsibilities (Eurostat).⁵ The woman and her family need the income of a full time job and in these countries part time work is often low-wage work with limited protection of the worker. To suggest that older women should move into part time work in order to manage elder care is to further the exploitation of women in marginal low wage work. Except in the Nordic countries and the Netherlands the part time work is characterized by low status, poor pay and precarious futures. It is gendered work and no doubt reinforces women's position of economic subordination as well as the ideology of female domesticity (Casaca, 2010). These patterns indicate that part-time work has been socially constructed as a female form of employment, since it allows women to keep their traditional responsibilities (caring/domestic duties) and to earn some money, without calling into question the men's long-established breadwinner role (Fagan, O'Reilly and Rubery, 2000).

Although the Nordic countries have provided "flexicurity" for older workers the "security" element comes from generous unemployment benefits. But in the current fiscal crisis these unemployment programs are also at risk of being cut. In fact, in Denmark

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⁵ Eurostat website, labour force survey: annual series. extraction: 23/08/2010.

there is already action to reduce the generous unemployment benefits that had provided the security in the context of a more flexible labour market (Alderman, 2010). Other countries are also facing a "fraying of the safety net" (Daley, 2010) which has been used by older women who are too young for official retirement benefits.

Special efforts to encourage employers to hire older workers may be counterproductive. Eleven out of the 15 original EU countries have had special programs to subsidize employers for hiring older workers, age 50 or over (Keese *et al.* 2006: 118-119). This method does not protect older women workers from gender discrimination, nor from discrimination on the basis of disability nor family responsibilities. In times of fiscal crisis why make these public expenditures when an elderly person in her family needs her care. The effort to solve one problem, the pension crisis would result in the creation of another problem, lack of care for the elderly and disabled and the short run expenditures of such subsidies would only add to the financial crisis. The use of employer subsidies to fix the problem ignores the value of older women's unpaid caregiving labor, essential for an aging population.

All of these precarious older workers are in need of training and up-skilling. But these opportunities are more limited for older workers, especially women who are viewed as less committed and more likely to retire soon. But training opportunities provided by European governments are also scarce and short-term oriented (except for Nordic countries), and tend to leave out older and non-skilled workers (Gallie, 2002) and especially older women (Pestana, 2004). As far as women are concerned, that attitude may also be explained by the fact that they are often busy with family responsibilities and do not think that they have time for the training programs or that the training programs will help them. This is especially the case for countries where familist and traditional gender ideologies prevail and public care services/facilities are insufficient. In the current difficult economic context, these workers are more likely to be vulnerable to labor market marginalization, irregular and low incomes and poverty.

Concluding Note: Preparing for the Future

In terms of EU policy there needs to be a comprehensive review of issues raise by the aging of the population and not just a narrow focus on the able older worker (gender unspecified) and the pension crisis. Pension policy, for example, cannot be divorced from the increased risk of chronic disease, work limitations and functional disabilities during the last years of working life. While it is important to acknowledge that many older workers are fully able to be involved in paid work after age 55, it is also important to recognize the diversity of health and ability among these older workers, as well as the gender disparities in chronic diseases and in care responsibilities for disabled family members. In addition, elderly women are more likely to need the hands on help of a family member not only because they live longer but also because they more likely to have 2 or more chronic diseases and are less likely to be married. This hands-on carework is essential to promote dignity in old age, and, even in the Nordic cluster, the hands-on help of family member is important. Workforce policy for an aging population cannot ignore the growing need for family care as well as the growing risk that the older worker herself will have limitations in the kind and amount of work that she can do. Public policy on active ageing as well as retirement tends to be gender blind while public policy for gender equality tends to be age blind. A new gendered social model for an aging population is necessary. Such a model cannot ignore the role of chronic diseases in creating age and gender friendly working environments. Neither can it ignore the growing need for family care among the very old.

Pension policies and unemployment policies, as well as disability benefits need to be reviewed in terms of the risk of chronic and disabling diseases among the population 50 and over. How much help will these older persons need? Of course the extent of help needed depends on the current and future prevalence of chronic diseases in the older population. The EU needs to take into account these chronic diseases in planning not only for labour market participation, but also in terms of health care for an aging population. Chronic disabling diseases need to be added to the EU goal of action "to prevent and combat the risks affecting the health of European citizens" Currently the EU

review of "threats to health" covers only communicable diseases⁶. For an aging population chronic disease is not only a threat to the patient's health, but also a threat to the caregiver's health. Caregiving needs to be understood as "productive work" and there must be adequate financial support available to family caregivers. And attention needs to be expanded to those chronic diseases which are likely to disable someone for many years, such as musculoskeletal conditions and those where the oldest old have a very high risk, such as Alzheimer's.

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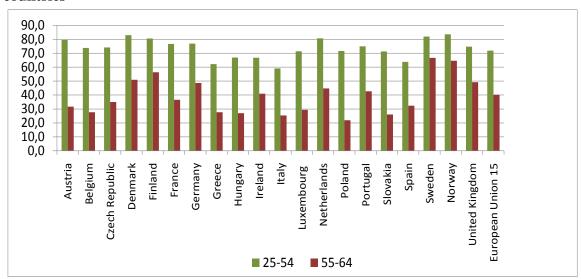
⁶ http://europa.eu/legislation_summaries/public_health/index_en.htm

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APPENDIX

Figure 1: Employment rates among women in 2009, by age, groups and by countries



Source: Eurostat, Labour Force Survey; Annual Series. Extraction: 23/08/2010