EUROCARERS' POLICY PAPER ON NON-COMMUNICABLE DISEASES AND INFORMAL CARE

BACKGROUND

Non-communicable diseases (NCDs), also known as chronic diseases, tend to be of long duration and generally slow progression, and the result of a combination of genetic, physiological, environmental and behaviours factors. The 4 main types of non-communicable diseases are cardiovascular diseases (like heart attacks and strokes), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes. Mental health is inextricably linked to NCDs and their outcome but is currently not considered as a NCD.

All age groups and all regions are affected by NCDs. Chronic diseases are often associated with older age groups, but evidence shows that 16 million of all deaths attributed to NCDs occur before the age of 70. Of these "premature" deaths, 82% occurred in low- and middle-income countries. Children, adults and the elderly are all vulnerable to the risk factors that contribute to non-communicable diseases, whether from unhealthy diets, physical inactivity, exposure to tobacco smoke or the effects of the harmful use of alcohol – NCDs are therefore largely preventable.

To lessen the impact of NCDs on individuals and society, a comprehensive approach is needed that requires all sectors, including health, finance, foreign affairs, education, agriculture, planning and others, to work together to reduce the risks associated with NCDs, as well as promote the interventions to prevent and control them.

Besides the loss of lives and the human tragedy that this always entails, the OECD[1] estimates that the premature deaths of 550,000 working-age people across European Union countries from chronic diseases, including heart attacks, strokes, diabetes and cancer, cost EU economies EUR 115 billion or 0.8% of GDP annually. This figure does not include the additional loss in terms of lower employment rates and productivity of people living with chronic health problems.

IMPACT OF CAREGIVING ON CARERS' PHYSICAL AND MENTAL HEALTH

Physical Health
Studies on caregiving's impact on physical health are less widespread and have received less attention than studies on carers' psychological health. Literature nevertheless shows that physical health

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[1] Health at a Glance: Europe 2016

outcomes can be linked to informal caregiving through the following dynamics: (i) caregiving often requires physically demanding work over a long duration, which might cause musculoskeletal injuries and aggravation of arthritis and other chronic illnesses; (ii) carers tend to neglect a healthy lifestyle (e.g., diet and exercise); and (iii) caregiving increases stress and lowers psychological health, which is likely to manifest in such physical outcomes as hypertension and cardiovascular disease.[2]

Caregiving often involves physical efforts and may produce physical pain. Individuals with psychological distress often present with physical symptoms, which is known as somatisation. A study on "informal care and carers health" in South Korea[3] suggests that carers may suffer multiple negative health effects across many domains of physical health. In addition to effects on specific measures of health, it also showed that health care costs of carers increase.

Carers have worse physical health than non-carers with significant differences in self-reported health, medication use, antibodies, and stress hormones. Physical health losses among carers are more likely to be related to their mental health status than to physical overload. At the same time, however, a high correlation exists between a care recipient's mental illness or a carer's depression and physical health. Dementia caregiving is particularly associated with lower physical health. The most severe physical impairments can be found among carers who are older, male, or in charge of dementia patients, a risk group slightly different from those identified in the psychological health research, in which women in particular perceive a higher cost of caring.

Some studies demonstrate that mortality rates are higher among carers who report emotional strain than among non-carers. On the other hand, carers who do not report a high burden from their tasks seem to have the same mortality risk as the comparison group[4]. According to empirical evidence, self-selection out of the carer role when the severity of the physical impairment makes care impossible may explain this outcome. Public support therefore reveals crucial to provide different options for selecting out of the carer role when the adverse health effects become too severe or at least reduce the care intensity. This being said, although it seems rational to assume that when carers have free choice, only those with robust health are likely to become carers, decreased self-rated health measures emerge from studies for both male and female care providers even after they account for self-selection.

Mental Health

While unpaid carers provide a valuable service to society and looking after family members or friends brings great rewards, there is growing concern about the increased psychological distress, strain and overall health deterioration endured by family carers. Isolation and the lack of support might prove a high burden and result in distress or mental health problems.

The majority of studies find a negative association between caregiving and psychological measures. They underline that mental impairment among care recipients negatively affects carers' well-being, an effect enhanced by financial restrictions and the lack of social support. The evidence overall suggests that carers tend to show an above-average level of psychiatric symptoms. Behavioural problems (e.g., disruptive and aggressive behaviour), physical and cognitive impairment, and the time spent on

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[2] Impacts of Informal Caregiving on Carer Employment, Health, and Family, J-M Bauer and A. Sousa-Poza, IZA, 2015
[3] Informal care and carer's health, Young Kyung Do et al., National Bureau of Economic Research, Working Paper Series, June 2013
[4] Caregiving Strain and All-Cause Mortality: Evidence From the REGARDS Study, M. Perkins et al., 2013

caregiving seem to place a burden on the carer and increase symptoms of depression, with behavioural problems being particularly important when caring for demented care recipients. Studies also show that dementia care is associated with higher levels of carer anxiety.

Overall, the prevalence of mental health problems among carers is 20% higher than among non-carers. There is no clear geographic pattern in prevalence with the difference in prevalence being highest in Greece and lowest in Switzerland. Women tend to have more mental health problems than men but the ratio in prevalence between carers and non-carers is higher for males. The gap also differs by countries among males and females. Female carers generally report higher levels of depression, anxiety, and lower levels of well-being, and the literature reviewed suggests almost exclusively stronger adverse effects for women than for men. Additional gender differences include a tendency for women to be more burdened by the caregiving experience than men, to perceive more caregiving costs, and have lower levels of life satisfaction. These large gender differences can be partly explained by the fact that women tend to provide longer and more intense care[5].

Mental health problems might be influenced by the intensity of caring. OECD data shows that in most countries there is a clear difference in mental health prevalence for very intensive care (more than 20 hours/week). On average, high intensive caring is associated with prevalence 20% higher than for non-carers, reaching even 70% or 80% higher in Australia, the United States and Korea. At the same time, caring with lower intensity (either less than 10 hours/week or between 10 and 20 hours/week) does not always lead to a higher prevalence of mental health problems than among non-carers. Other differences between carers and non-carers might influence their mental health.

For instance, carers might be older or have other socio-demographic characteristics which make them more prone to worse mental health. Current mental health problems also depend to a high extent on previous mental health status. The detrimental impact of caring on mental health also reveals stronger in the case of co-residential care[5].

Perceived social support and coping strategies reduce these downturns and increase carer well-being. Yet, OECD studies show that being the recipient of a carers' allowance does not seem to significantly alter the negative impact on mental health in Australia and the United Kingdom (where information on allowances exists).

A small stream of literature finds that being a carer can have positive impacts, including companionship, fulfilment, and enjoyment. Positive outcomes are, however, rare or at least dominated by negative effects. Experiencing such care outcomes is indeed negatively related to depression, burden, and self-assessed health.

IMPACT OF INFORMAL CARE ON CARE RECIPIENTS' HEALTH OUTCOMES

Research shows that dementia care outcomes for patients are improved when families are engaged in patient care, families enable the postponement of institutionalisation, and patients who receive assistance were more likely to adhere to treatment. Conversely, the absence of adequate caregiving is associated with problematic hospital discharges or readmission.

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[5] Help Wanted? Providing and Paying for Long-Term Care – Chapter 3 'The Impact of Caring on Family Carers', OECD, 2011

In 1996, Vicki Freedman studied the impact of families on the use of institutional care in her analyses of nursing-home admissions in the United States. She identified three different interrelated ways in which family members might influence admissions: 1) family members could give personal care directly to the older person; 2) family members could provide assistance in obtaining formal community-based services; and 3) family ties could have a beneficial impact on the well-being and health of the older person, and thus indirectly affect the risk of admission[6].

KEY MESSAGES

Informal carers are the backbone of any long-term care system. Across EU countries, between 50 and 100 million people provide (usually unpaid) care to people with functional limitations. Close to two-thirds of such carers are women. Support for Informal carers is often tokenistic, provided as recognition that they perform a socially useful and difficult task. But supporting Informal carers effectively is a win-win-win solution. It is beneficial for carers. Without support, high-intensity caregiving is associated with a reduction in labour supply for paid work, a higher risk of poverty, an increased risk of unhealthy behaviours and a 20% higher prevalence of mental health problems among Informal carers than for non-carers. It is beneficial for care recipients, because they often prefer to be looked after by family and friends and to remain at home for as long as possible. And it is beneficial for public finances, because it involves far less public expenditure for a given amount of care than the estimated economic value of family caring.

Health promotion and disease prevention

Health promotion is the process of empowering people to increase control over their health and its determinants through health literacy efforts and multi-sectoral action to increase healthy behaviours.

- More funding should be allocated by the European Commission and EU Member States to preventive measures. As a result of the financial turmoil, many European countries have adopted drastic measures that have seriously affected access to care for chronic non-communicable disease patients. Yet, the economic crisis could be turned into an opportunity to explore new and innovative ways of tackling chronic diseases. Specific attention should be paid to the situation of carers as a group at risk given the demonstrated impact of caregiving on carers' health;

- Several Council Conclusions address health inequalities.[7,8] Member States should now implement them. Simple steps include improved access to good quality air, water, food, sporting, recreational and cultural facilities and green space. They all contribute to reducing inequalities as well as helping to create sustainable communities. Developing a carer-friendly environment, i.e. the combination of support (information, training, respite care, etc.) as well as empowering (flexible working hours, carers' leave, access to formal care options, etc.) measures has the potential to greatly improve carers' health outcomes. The European Commission can aid this process by facilitating exchange of best practice.

- We need to measure, monitor and report on action taken in the Member States on chronic diseases. To facilitate monitoring and reporting of progress, a number of targets could be set e.g. 25% reduction in mortality by 2025. Much more must be done to tackle the causes of ill health rather

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[6] Freedman, V. A. 1996. Family structure and the risk of nursing home admission, The journals of gerontology. Series B, Psychological sciences and social sciences 51(2): S61–9

[7] http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/114994.pdf

[8] http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/126524.pdf

than cure its consequences. It is time to recognise health promotion as an investment with significant economic and welfare gains.

Counselling and training services

Training and information are currently provided in 17 countries across Europe and counselling in 12 countries. According to surveys, carers would welcome more psychological counselling and information from health professionals. For instance, carers are not always knowledgeable about the disease of the person they care for or have difficulties dealing with disabilities. Counselling has been found to be effective at relieving carer's stress. Most social support and training is typically provided through local initiatives and relies heavily on the voluntary sector. Many local community organisations and NGOs offer social support and counselling programmes, making them often more widely available to carers than respite services but are often provided in informal settings or as a crisis response. Informal counselling is often provided through support groups which have developed at the local level to provide a listening ear and a forum to exchange experiences. Some country initiatives are promoting a more comprehensive and integrated counselling system. Sweden has promoted a better space for dialogue between the socio-medical sector and the families and friends of disabled. "Caring for Carers" in Ireland developed a comprehensive network of support institutions for carers, which offer 13 skills training courses called "Caring in the Home". The Netherlands uses a preventive counselling and support approach (the POM-method or Preventieve Ondersteuning Mantelzorgers). Once enrolled in national care plans, individuals are contacted by trained social workers who carry out house visits. These workers provide carers with information and follow-up phone interviews on a three-month basis to prevent the occurrence of mental health problems among carers, especially at the early stages of caregiving. In the United States, the National Family Carer Support Programme includes support groups and individual counselling, workshops and group work.

Respite care

Respite care is often perceived as the most important and common form of support to alleviate caregiving burden and stress. Respite care can provide carers a break from normal caring duties for a short period or a longer time. Without respite, carers may face serious health and social risks due to the stress associated with continuous caregiving, and may also enjoy little time for leisure or feel isolated. Carers are often reluctant to take such breaks because of uncertainties about the quality of respite care and financial difficulties. Policies ensuring ease of access to respite, for example via financial support to pay for such breaks, geographical proximity and sufficient availability of respite services, are thus important.

Respite care may refer to very different types of interventions providing temporary ease from the burden of care. Often, the objective of such breaks is to increase or restore the carer's ability to bear this load. The most common forms of respite care include Day-care services; In-home respite; and Institutional respite. An important element of respite care definition is the length of respite. Some of the services offer short stays (such as day-care services) and others consider longer periods of time (vacation breaks for carers, emergency care etc.). Both duration and frequency of respite breaks (every day or week) are relevant when assessing the importance for the carer and the care recipient. Some countries offer more diversified "packages" of support (combining both short and long-term breaks) in order to better meet the needs of the carer. The provision of respite breaks can be provided in various settings, such as community care or institutions, and by various actors, such as family and friends, and nurses.

Respite care services are the most common type of services and are provided in 21 European countries. Respite care results in satisfactory outcomes for carers but is not cost-effective for all forms of service provision. Assessment of the effectiveness of respite is complex because of the multiple dimensions of impact on informal caregiving (mental and physical health, satisfaction or admission in institutions), but recent evaluations show that carers highly value such services. The impact may be higher for high-intensity carers and day care appears to be more effective for carers in paid-employment and where the person cared for has cognitive problems. Overnight respite care has proven to be effective at reducing the subjectively reported burden of carers.

A range of services is probably most appropriate, to provide flexibility of respite provision and responsiveness to carer and care recipient characteristics and needs, and also changes in those needs over time. More tailoring of respite to the needs of carers instead of fixed hours and days is cited as a suitable option. Mixed forms which include in-home care on demand and drop-in services combined with more traditional forms of respite also appear to be useful for carers. As some users of adult day services spend a considerable amount of time in travelling and preparations, combining respite care with services for planning and transportation of the dependents is likely to alleviate the burden of carers.

Information and co-ordination services

Carers may not be fully aware of services available to them and may find it difficult to get help from fragmented services. Eligibility criteria for allowance or tax benefits and credits can be confusing and carers may require help from other Informal carers or social workers. Internet websites and other discussion boards provide useful information to the carer, though they are often left alone to tackle administrative issues. Daily planning of different tasks and duties may be difficult for carers and can cause burnout. Doctor's appointments, organisation of respite care breaks or social workers appointments may be difficult to co-ordinate, especially when combined with personal or familial duties and employment. One-stop shops for carers and their families can better inform and help carers. Such information centres help carers be in touch with others having similar experiences and acquire information on sources of help (financial, physical, emotional and social), and on the care recipient's illness or disability. For instance, in France, the Local Centres of Information and Co-ordination (CLIC) provide information and help on all topics related to and elderly needs. Help is provided individually and social workers meet with carers on a regular basis. These centres also link carers with medical staff to address questions related to the disability of the care recipient. Linking the efforts of private, voluntary organisations and community associations with public authorities can also be important to reduce fragmentation and improve co-ordination of services. In Bremen (Germany), Social Services Centres inform and support carers throughout the caregiving spells and also help co-ordinate medical and social sectors. These centres are partly funded by NGOs and communities but also receive grants from the city of Bremen.

Case (or care) managers can help alleviate the administrative burden of carers and help them co-ordinate their needs and those of the person cared for. A case manager playing the role of a co-ordinator between the different health and social services can simplify significantly the follow-up procedures of carers. An example of such case management can be seen in Austria, where local centres evaluate carers' needs and help them find appropriate services. Support services are available in different social service centres – such as the Vienna Health and Social Care Centres and the Tyrolean Integrated Social and Health Care Districts. They provide help with different dimension of planning,

organisation and information. Carers who enrol in local support centres are put in contact with a district nurse who assesses the carer's needs and directs the carer towards appropriate entities and services. Administrative and co-operative tasks are the primary focus of these institutions, but the services also act as brokers and contacts between clients and formal service. The aim is to avoid gaps between health and social care provision and empower carers with knowledge and skills to face the difficulties of caring duties. Carers' assessment is a first step to define which services are needed for carers but does not necessarily mean that all carers are identified and receive support services. Several countries including Australia, Sweden and the United Kingdom have developed protocols for appropriate assessment of carers' needs, helping professionals to define carers' daily tasks and identify stressors. There is often no mandate for carer assessment except in the United Kingdom, resulting often in lack of resources to perform systematic assessment. Even where the assessment is mandated, an estimated half of carers are not known to service agencies (Audit Commission, 2004). The reasons, besides lack of awareness and self-identification as carers, include lack of knowledge of entitlement and difficulty asking for help.

Identifying carers through actors that carers see regularly is key because many carers are not forthcoming in asking for help. General Practitioners, nurses, pharmacists and other health professionals are well placed to recognise and advice carers because of their frequent interaction with the care recipient or simply through normal consultations. In Scotland, GPs have been given incentives to identify carers, set up carer registers and refer carers to appropriate local support. A resource pack is distributed in each GP practices and GPs (and other primary health professionals) are connected to carers' centres. While it is unrealistic to expect that GPs and other primary health professionals will be able to provide all necessary information and counselling to carers, they can be well placed to refer carers to more specialised sources of information and advice.

Patient empowerment and integrated care

Health care needs are becoming more complex; ageing populations are leading to more chronic illnesses and multi-morbidity. This means that coordination of care is increasingly important, including in primary care itself. The provision of coordinated care is an increasingly complex activity, as people's needs become more extensive and they are cared for across many settings and professionals. Moreover, there is increasing emphasis on the 'goals as defined by the patient in terms of quantity and quality of life'. Coordination requires integrated patient records, IT-based remote or social media approaches, and a more empowered role for individuals and their carers.[9]

To cope with chronic diseases, health systems need to stop being disease-centred and adopt a person-centred approach, where self-management, community and specialist medical care and social care are integrated in highly personalised solutions centred on the needs of the patient. The patient, in this vision, is an active and equal partner and truly a "co-producer" of well-being. This implies changes at all levels in how care is structured and delivered. It also implies a profound change in medical culture and societal attitudes. And, it implies the empowerment of patients and their carers and their participation – not only in care, but also through participation in policy-making, in evaluating and co-designing care services, and in research to develop new therapies that meet patients' needs more effectively.[10]

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[9] Definition of a frame of reference in relation to primary care with a special emphasis on financing systems and referral systems, EXPH - 2014
[10] Preamble to Charter of patient empowerment developed by the European Patients' Forum

The role of care professionals

Although questions remain about effective interventions, there are many things that (primary) care professionals can do to support informal carers — most of which are neither time consuming nor expensive in terms of resources.

These include the need to:
- Acknowledge carers, what they do, and the problems they have.
- Flag the notes of informal carers so that in any consultation you are aware of their circumstances.
- Treat carers as you would other team members and listen to their opinions.
- Include them in discussions about the person they care for.
- Give carers a choice about which tasks they are prepared to take upon themselves.
- Ask after the health and welfare of the carer as well as the patient.
- Provide information about the condition the person the carer is looking after suffers from.
- Provide information about being a carer and support available.
- Provide information about benefits available.
- Provide information about local services available for both the person being cared for and the carer.
- Be an advocate for the carer to ensure services and equipment appropriate to the circumstances are provided.
- Liaise with other services.
- Ensure staff are informed about the needs and problems of informal carers.
- Respond quickly and sympathetically to crisis situations.