

THE IMPACT OF CAREGIVING ON INFORMAL CARERS' MENTAL AND PHYSICAL HEALTH

The correlation between caregiving and physical and mental health is well established. In particular, research has traditionally highlighted the negative consequences on carers' health, by focusing on the stress and burden associated with caregiving. Caring for a dependent family member presents all the features of a chronic stress experience: it creates the physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance.

As a result of these stressors, the carer may experience psychological distress symptoms, such as anxiety and depression, which may – in turn – negatively affect the carer's physical health. Besides, the physical health is negatively affected by caregiving responsibilities, not least because carers are less likely than others to meet their own health needs. This can result in harmful habits and lifestyles (e.g. smoking, inadequate food or sleep habits) and failure to take preventive health measures (such as medical consultations).

Evidence shows a progression of negative effects: carers first experience distress and depression, which are followed by physiologic changes and impaired health habits that ultimately lead to illness.

The prevalence of mental health problems among informal carers is 20% higher than among non-carers and particularly high for people who provide very intensive care (more than 20 hours per week). Depressive disorders, anxiety, anger and hostility are frequently associated with heavier caring duties. (OECD, 2011)

More recently, researchers have started to identify some positive aspects of caring, which contribute to the carer's satisfaction with life and psychological wellbeing. Recent findings suggest that helping others may be just as beneficial to health as receiving support: caregiving makes carers feel good about themselves, gives meaning to their lives, enables them to learn new skills, and strengthens their relationships with others. Researchers have thus questioned the specific features and circumstances that make carers more resilient, that is, able to maintain wellbeing while caring for others. It has emerged that the health and well-being of carers is a complex area with perceived satisfaction and burden varying from one individual to the other and which depends, in part, on the availability of appropriate support from both the formal sector and informal caregiving networks.

The drivers of carers' wellbeing

Recent research has highlighted different factors which can influence carers' satisfaction with life (SWL), i.e. their subjective wellbeing.

First, the factors related to caregiving and care recipients associated with low levels of SWL include:

- The intensity of care
- Being the primary carer
- The care recipient's advanced age and high level of disability/dependency
- Being the carer of a person suffering from dementia

- Living with the care recipient
- Having a bad relationship with the “caree”
- The ability to help the “caree”

Caring for a patient with dementia is more challenging than caring for a patient with physical disabilities alone.

Providing help that fails to improve the quality of the patient’s life may lead to frustration, resignation and negative health effects for the carer. On the contrary, providing help that significantly addresses the needs and desires of a patient is likely to uplift the carer and contribute to positive health effects.

The factors associated with socioeconomic conditions and levels of support that increase carers’ life satisfaction include:

- Having a high socio-economic status
- Having a good level of social and family support and being satisfied with the latter
- Ability to engage with social activities
- Having access to respite
- Being in employment

According to the 3rd European Quality of Life Survey, 14% of non-working carers feel depressed all or most of the time, which is more than twice as high as the corresponding figure for working carers.

Among the psychological factors associated with greater SWL:

- Being healthier, having high vitality and lower stress level
- Involvement in spiritual or religious practices
- Having a positive appraisal of caregiving
- Having a positive view about themselves
- The ability to accept and adapt to their life as carers

Resilience is the ability to adapt to the challenging situation that caring generates. It is a crucial factor influencing the coping strategies a carer develops and applies, with subsequent effects on personal wellbeing. However, resilience has clear limits and may not be sufficient to guarantee good mental wellbeing when the situation and risk factors become prolonged in time and intensity.

Some of the factors indicated above are individual and cannot be influenced or changed by social policy measures. Others – such as organising accessible long-term care; providing respite care for informal carers to allow them to take care of themselves and participate in non-caring activities (such as sports or social activities); and enabling family carers to balance work and care – can and should be driven by social policy.

What can be done to improve carers’ wellbeing?

With regards to promoting carers’ health and wellbeing, there are two main possible approaches that should ideally be combined. Firstly, the provision of more adequate and intensive formal care services to the cared-for person (hence reducing the intensity of informal care and the burden on carer).





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A second option is the provision of direct support to carers, ranging from respite care to training, counselling and psychological support.

Respite care

Respite care is often perceived as the most important and common form of support to alleviate the caregiving burden and related stress. It consists in offering carers a break from their caring activities, in order to temporarily reduce their workload and enable them to continue to provide care over a long period of time. The most common forms of respite care include day-care services, in-home respite and institutional respite. A form of longer break can be vacation breaks for carers.

Nevertheless, carers often feel reluctant to take such breaks because of uncertainties about the quality of respite care provided and financial difficulties. Hence, it is important to ensure that the services provided are suited to the dependent person's needs and are well managed and staffed with licensed professionals. 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 equally important. Flexibility of respite care (e.g. respite available in hours and days in line with carers' needs) should be considered, as well as the possibility to combine respite care with services for planning and transportation of the dependent.

Counselling and training services

Recent surveys show that carers would welcome additional 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 proved effective to relieve carers' stress. Across Europe, most social support and training is typically provided through local initiatives and relies heavily on the voluntary sector. Linking the efforts of private voluntary organisations and community associations with public authorities can be important to reduce fragmentation and improve the coordination of services.

Information and coordination of services

Carers may not be fully aware of services available to them and may find it difficult to get help from fragmented services. The internet is a source of useful information to the carer, although they are often left alone to address administrative issues. Daily planning of tasks and duties may be difficult for carers and cause burnout. Dealing with doctors' or social workers' appointments and organising respite care appointments may be difficult, especially when combined with personal or familial duties and employment. One-stop shops for carers and their families, i.e. information centres where carers can get the info they need on the help at their disposal (financial, physical, emotional and social) and the caree's condition can prove extremely beneficial to carers' wellbeing.

Case (or care) managers

Carers often find themselves coordinating scattered health and social services. The support of a case/care manager can help alleviate the administrative burden facing carers following an assessment of their needs and those of the person they care for. Managers allow to bridge gaps between health and social care provisions and empower carers with knowledge and skills to face the worries related to their caregiving duties. Professional case/care managers nevertheless need to reach out to carers in a proactive way since they are not always forthcoming in their search for help, may be overburdened by their caring activities or simply afraid to

shed light on their own limitations. Identifying carers through adequate professionals trained to support them is therefore key: general practitioners, nurses, pharmacists and other health professionals are all well placed to detect and advise carers refer or to refer them to a more specialised source of information and support.

Health promotion and disease prevention for carers

Carers usually appreciate routine health 'check-ups' that are targeted at them. It is recognised that a holistic carer assessment is an important step in providing timely, responsive information, advice and support that match the preferences and needs of the individual carer concerned. The identification of carers in the national health and social care systems is crucial to enable systematic data collection, to target carers and to inform them about the range of support available to them.

Reconciliation measures

Allowing carers to remain in work can also be helpful to increase their wellbeing.

In conclusion, if not adequately supported, carers risk to become patients themselves. This is even more likely in the light of demographic ageing since the population of carers itself is growing older. As a result, carers might no longer be able to satisfy the increasing demand for long term care (with serious sustainability issues for European welfare systems) and will convert into a burden for public finances (as they will also require care). If European States want carers to keep on providing care, it is in their interest to put in place adequate long-term care policies and practical support measures for carers.

References

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