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Informal caregivers in Italy: the 'phantom zone' of welfare

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Abstract. Medical progress and the consequent gradual ageing of the population increase the number of people in Europe who require continuous care, as they suffer from chronic diseases or senility. This demand is disproportionate if compared to the economic resources of health systems and is, therefore, heavily supported by the activity of the so-called "informal caregivers". With our article we propose to depict the current scenario in Italy, dwelling on the safeguards, to date, aimed at informal caregivers, which are insufficient to correct the criticalities associated with the burdensome assistance provided by such figures. Such critical issues result in a real risk for the health of informal caregivers and their loved ones and require urgent action by the health system. If it is true that health welfare is not able to protect the increasing number of people who are not self-sufficient, it is necessary to invest at least on specific measures to preserve the health and skills of those who are at the forefront of this hidden welfare. (www.actabiomedica.it)

Key words: National Social Insurance Agency, Caregivers, Handicap, Disability, Social Care

The "formal caregiver" (FC) is a health professional (health worker, nurse, physiotherapist, psychologist, educator) or a carer who provides assistance – for a fee - to people who are not self-sufficient.

Instead, "informal caregiver" (IC) or "family caregiver" refers to a person who takes care, on a non-professional and free basis, of a loved one (i.e., family members, friends, and neighbours) who is not self-sufficient and in need of long-term care because of old age and/or suffering from chronic, disabling diseases.

A survey carried out by the Italian National Statistical institute (ISTAT) on the theme of "Reconciliation between work and family life" revealed that in 2018 in Italy there were a total of 12 million 746 thousand persons aged between 18 and 64 (34.6% of the total population in this range) who cared for children under 15 or sick, disabled, or elderly relatives (1).

In Italy, the 'formal caregiver' is for all intents and purposes one of the recognized professional figures and, therefore, enjoys economic and pension rights; on the contrary, the 'informal caregiver' is not a legally recognized figure and enjoys very little protection, especially in comparison with other European countries. To date, the only legal safeguards granted to informal caregivers are those contained in Law 104 of 1992 (2-4).

Art. 3 of the law defines the handicapped person 'a person with a physical, mental or sensory handicap, stabilized or progressive, which is the cause of learning difficulties, of relationships or of occupational integration and which is likely to lead to a process of social disadvantage or marginalisation'. Moreover, the legislation specifies that the state of disability has a connotation of 'severity' if the disability reduces personal autonomy so as to make necessary a continuous and comprehensive assistance intervention in the individual and in the relational sphere. In Italy, the assessment of the condition of disability is carried out by local health companies through a specific collegial medical commission, under the aegis of the National Social Insurance Agency (INPS).

Therefore, the Italian law guarantees the medical assessment of the state of disability, recognizing that the person suffering from 'serious disability', because of his disability, needs a 'continuous and global' assistance in its individual and in its relational sphere. However, once the status of serious disability has been recognised, the National Health System itself is not in a position to assure to the individual the respect of this continuous right of care, leaving it de facto to the family members and/or cohabitees who eventually assume the role of 'informal caregivers'.

Law 104/92 provides very little safeguards to the benefit of caregivers, mostly related to the work sphere. As stated in art. 33, informal caregivers are granted the possibility of selecting, e.g., if state-employed and where possible, the place of work closest to home. In addition, the law grants the recognition of justified hours of absence from work (for a maximum of 3 days per month) dedicated to the care of a dependent family member over the age of 3.

Parents who take care of children under 3 years of age are granted the possibility of extending the period of optional abstention from work up to three years, provided that the child is not admitted full-time to specialized care institutions. Alternatively, they are granted two hours of paid daily leave until the child reaches the third year of life.

These benefits have considerable limits of accessibility: they are to the advantage only of IC that prove to be cohabiting with people suffering from a proven serious disability. Moreover, only one person per household can enjoy these benefits.

At the end of 2020, the Budget Act 2021 (5) established a new Economic Fund for the recognition of the social and economic value of the non-professional care activity carried out by the family caregiver. The IC assisting disabled persons - pursuant to Law 104/92 - can apply to the National Social Insurance Agency to try to obtain an economic bonus to support their activity. The financial compensation is however symbolic and far from appropriately rewarding the complex activity carried out by family caregivers; moreover, the economic fund can satisfy a very limited number of applicants across Italy, selected on the basis of income and the level of severity of the assisted person's disability.

Challenges and opportunities

The support policies of informal caregivers currently present in Italy are far from protecting this figure and are not appropriate when considering both their important contribution to health Welfare and the burdensome and exhausting commitment required by this figure.

The IC has to personally manage even very complex pathologies, despite not having any specific competence in this regard.

This can lead to both negative consequences on the health of the person receiving the treatment, as well as to a perception of inadequacy felt by the caregiver, who is facing an activity for which he/she is not qualified.

The tasks required of the caregiver are variable according to the type and severity of the disease of the subject he or she is assisting; in any case, they are very expensive and aim to meet all the needs related to the overall care of the person. The activity of the caregiver is not only limited to meet physical and domestic needs, but also extends to the administrative activities that the same is not able to carry out independently (6).

The demanding activity required and the emotional context in which it takes place inevitably have an impact on the quality of life of the caregiver, with consequent serious health risks (7-9). The burden of the considerable effort required from the IC, inevitably results in the family caregiver to neglect their state of health, delaying or not performing routine screening at all. The serious health impact of caregiving is demonstrated by the fact that caring for sick spouses is an independent risk factor of mortality for caregivers (7-9).

This evidence makes urgent and necessary an intervention by the health system to protect the health of the caregivers. It is indeed necessary to ensure that such persons receive counselling and training, as well as psychological and health support to guide them in the exercise of their duties. Such gap is certainly not filled by a one-off economic benefit nor from few hours of work permits, which today are the only protections foreseen for the informal caregivers in Italy. Instead, is desirable to provide informal caregivers indispensable resources of national welfare, concrete health support for their own health and for the health of their loved one, which are predictably interdependent.

It is essential that the NHS invests more in respite care which is an essential tool to allow the disabled to acquire autonomy and social skills even outside the family environment. This implementation is in line with the constitutional principles of Law 104/92 or with the objective of ensuring the disabled person the attainment of the fullest autonomy possible, promoting social integration.

The national Welfare, incapable of directly assisting the numerous not self-sufficient subjects in Italy, should at least guarantee the maximum protection of informal caregivers to whom it entrusts this onerous task. It is extremely urgent to address and get out in the open the remarkable criticalities connected to this hidden phenomenon.

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