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advantAGE
MANAGING FRAILTY

Empowerment of citizens and tackling frailty: The point of view of the 'Active Citizenship' Association from Marche region



Monia Mancini the Regional Secretary of 'CittadinanzAttiva' (Active Citizenship – Marche region) - an association dealing with the promotion and protection of citizens' and consumers' rights - describes the perspective of the association on empowerment of citizens and frailty.

The following is a combination of an in-person interview in occasion of the ADVANTAGE JA National Stakeholder meeting for Italy and of a phone interview which took place at the beginning of December 2018.

Q (Question): Active Citizenship is part of a European network dealing with the protection of citizens and the services provided to them, as well as being active in patient empowerment. What is the role of Active Citizenship in the European negotiations on citizens' empowerment?

A (Answer): Our association is the leader of the Active Citizenship Network, based in Italy and recently with a representative office to the EU in Brussels. It is a European network of civic organizations with the aim of developing an active citizenship and promoting participation in the areas of consumption, of corporate social responsibility, and of healthcare. The empowerment of citizens is the base and the purpose of our association. A self-aware and informed citizen takes better care of himself/herself, thus resulting in benefits for the healthcare system. To date, Active Citizenship Network has carried out many activities in this field. The first achievement was the approval, in 2002, of the European Charter of Patients' Rights. Then, since 2007, it has been established the European Day of Patients' Rights. Another important initiative concerns the Second edition of the European Civic Award on the fight against chronic pain, a project that rewards good practices at European level on the management of chronic pain, with a specific section dedicated to the empowerment of citizens.

Q: Would dedicating a section of the Erasmus+ programme to the beneficiaries of empowerment services set an example?

A: At European level, the Erasmus+ programme offers good opportunities, for example with adult education among its objectives.

Q: What is the definition of frailty in older people from the point of view of the citizens and of a citizens' association?



A: Frailty occurs when it is not possible to maintain a full state of well-being at 360°, defined as quality of life in terms of health (such as being able to answer to health needs), social inclusion (being able to maintain relationship) and economic situation (a welfare system meeting the needs of care of older people). The maintenance of this level of quality of life requires that all the actors involved in the above aspects - such as institutions, healthcare professionals and social workers - work together in synergy and no longer in silos as they do today.

Q: From the Stakeholder's point of view, what are the new needs related to frailty?

A: Frailty has various levels and areas, such as social, economic, geographical, in which the citizen/patient has an important role. Empowerment is a tool that cannot be ignored, for example to achieve therapeutic adherence, and therefore it constitutes a tool for preventing frailty.

Q: In your opinion, do current policies respond to the need of addressing frailty in older people at 360°?

A: Unfortunately, there is still much more emphasis on the health aspect and less on the social aspect. The main problem policy makers have to face is choosing the appropriate a welfare system and whether to focus on the provision of services or on the provision of economic contributions (e.g. benefits). The current situation, which is characterised by a combination of the two, is not sustainable in the long term. This complex issue needs more attention from the policy-makers.

Q: Is there a need to create new services to meet the needs of a population with an increasing life expectancy?

A: The management of frailty, outlined at European level, is then implemented, through specific interventions, at local level. This is possible through a network of organizations and processes, such as, for example, social areas, Mayors, district directors. The participation of citizens in these processes is very important, as it is the promotion of specific initiatives suggested by the citizens themselves.

Q: As you said, frailty should be addressed through the synergy and joint work of policy-makers and stakeholders. What is the situation in Italy about this issue?

A: In Italy, there are some experiences in this area. Some examples are the "Community Care Homes" (Case della Salute¹) implemented in Emilia Romagna and Lombardy regions (the latter focusing more on social aspects), the Communities of Practice of Friuli Venezia Giulia (intended to take care of frailty at all levels, not only in old age), or even the Guidelines on Frailty developed by Tuscany Region. However, these experiences are local, fragmented and sporadic, thus producing inequalities, which in turn have an impact on patients, who receive different healthcare or services depending on where they live. There is the need for an overall vision and implementation and for guidelines at national level, including funding, that would pave the way for ensuring that frailty is addressed in the same way throughout the territory.

Q: In Italy, the concept of frailty is quite broad and inclusive, comprising for example disability, mental illness, children. When considering older people, however, there is generally more attention to chronicity and health aspects. Do you think it is appropriate to talk specifically about frailty in older people, separating it from the general concept of frailty, or can we continue to consider it as an integral part of the general concept?

¹ The term "Case della Salute" in Italy is commonly used by several Italian Region for indicating however different care services



A: In my opinion it is not good to consider frailty altogether, comprising for example disability, mental illness, children, because frailty in older people has its peculiarities. Frailty of older people should be an integral part of the broader concept of frailty, but then it requires a specific focus, both for its distinctive features and because it represents the challenge that future National and European governments will have to face, also in terms of budget. The current Italian context is characterized by a lack of a generational turnover, a decrease in birth rates and, according to the latest ISTAT (Italian National Statistical Office) data, an increase in deaths. Therefore, it is absolutely necessary to focus on the frailty of older people, also in terms of expenditures, for example on how much and in which way European countries intend to invest in the care of frail older people. Unfortunately, services and interventions are scarce, especially for frail people living in vulnerable and disadvantaged areas. In these cases, frailty reaches its maximum expression in a negative sense. One possible solution is to plan interventions comprising new technologies, telemedicine and remote assistance.

Q: On December 13th 2018, in Madrid, the ADVANTAGE JA Coordinator will present the "Frailty Prevention Approach" (FPA), a common approach to frailty to be used in Europe to overcome the differences between European countries. Subsequently, in 2019, the document will be widely disseminated and we will contact the Member States to understand, at governmental and regional level, how they plan to implement this document in practice. In this context, are there any policies, strategies or initiatives, national or international, that you consider valid or that we should draw on?

A: At international level, I am not aware of any initiatives on frailty except for ADVANTAGE JA, in which I have been involved. I really appreciate the work you are doing in the JA because it has a practical approach. I therefore call for the FPA to become an imperative to act and to be implemented by the EU through official regulations - such as a Directive - in order to be translated into rules for the Member States. This is a prerequisite for the FPA's objective to be achieved, at both the European and national levels. This is also in accordance with a Declaration of Intent signed in Tokyo in December 2017 by WHO, the World Bank, UNICEF and Japan, which say: "*the right to health belongs to the category of human rights and everyone must benefit from it, regardless of who they are, where they live, or how much money they have, and states must commit with public funds to ensure that health is guaranteed as a human right in every state*" (#HealthforAll; <https://www.who.int/mediacentre/events/2017/uhc-forum-2017/en/>).

Read more about the Marche region Active Citizenship [here](#) and [here](#).

Read more about the activities of the Active Citizenship Network [here](#).