

# From the 'expert patient' to 'expert family': A feasibility study on family learning for people with long-term conditions in Italy

## ABSTRACT

### KEY WORDS

Family learning, expert patient, chronic disease, welfare system, sociology

*The Italian welfare system has been identified as a 'familistic' system since the family is mainly responsible for taking care of its members in times of vulnerability. This situation seems to be a problem, not only because of the financial, social and psycho-social costs borne by families, but also because care work may be provided by the various caregivers with insufficient competence. As such, public services should foster family participation in their care-assistance plan, enhance their competences, and sustain them at an emotional level. This approach widens the notions of the 'expert patient'. It is the family that should become competent and involved as much as possible in the care processes. One way to achieve this aim is by implementing a programme of Family Learning for people with long-term conditions. This has been the object of an innovative feasibility study conducted in 2008 in a region of central Italy. This study explored whether families are actually ready to take on the self-management of long-term conditions and which surrounding conditions are necessary to manage them.*

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## Introduction: Changes in family structure and welfare policies in Italy

The demographic, economic and social changes that have been taking place in Italy over the last few decades have had a dramatic impact upon both family structure and the socio-demographic features of its components. The fall in fertility rates, longer average life expectancies, and the fall in death rates are among the factors that have most contributed to

the progressive ageing of the population (Frova *et al* 1999). The ageing index has doubled over the last 50 years and population forecasts indicate that this will grow exponentially over the next 50 years, raising the ageing index to almost 35%. According to demographic forecasts no other country in the European Union is likely to reach this level (Tognetti Bordogna 2007).

Families have been increasingly characterised as 'one-person' families (i.e. formed by one, often old, individual living alone), 'single-parent families' (i.e. formed by one widowed or separated/divorced parent and one or more children), or 'extended families' (where three or more generations live together). The continued presence of grown up children (up to 30 years old) in their parents' houses, the cohabitation with their own old parents, define a family where people who are 50–70 years old give 'social