

IN ILLNESS AND HEALTH: WHO RULES?

As long term conditions are spreading throughout Europe, participating strategies to help patients take control of their health need to become a health agenda priority

Due to the demographic changes happening in the last decades, Western society is growing old.¹ As it is well known, in Europe, this ageing process is causing an increase in the number of people who have one or more long term conditions. Consequently, concepts like chronic illness, long term conditions and long term care are becoming essential components of professional healthcare routines. The World Health Organization defines the term 'chronic illness' as "a process of long duration and generally slow progression that requires ongoing management over a period of years or decades".¹

In Europe the experience of living with chronic illness is becoming a priority in many chronicity strategies and mandates,^{2,3} which advocate not only the control of symptoms and adherence to treatment but also an increase in quality of life and, more importantly, self-care and a better adaptation to the illness and health continuum. Consequently, self-care and self-management strategies have been strongly established to incorporate these new trends in education, research, health policy and services in Europe and to promote the active involvement of patients and families in the decision making and education process.³

Long term conditions

When it comes to long term conditions there is clear evidence that shows their complex consequences not only for the individual but also for families.⁴ In this regard, the psychosocial impact of long term conditions can affect some European countries' financial sustainability, especially where austerity policies have been adopted. Lately, it can be observed that European social and health policies have moved from focusing on the different pathologies to an increased interest in how people perceive, respond to and live with an illness. This proves that each person's perception of an illness is unique, unrepeatable and independently based on the type of long term condition they have. Therefore, considering this, the formula 'one size fits all' cannot be used anymore and a change of culture is needed.

Nevertheless, we can find several limitations to tackling these individual needs: 1) The lack of health policies and programmes integrating policy agenda priorities, third sector range of services and patients'/families' needs; 2) The lack of instruments and



Dr Maria Carmen Portillo research projects which reflect the holistic complexity of a long term condition and the interaction of different agents in the adaptation process; and 3) The need for further funding to support those initiatives and research projects which promote the association of patients, families, voluntary organisations and formal services in the management of long term conditions.

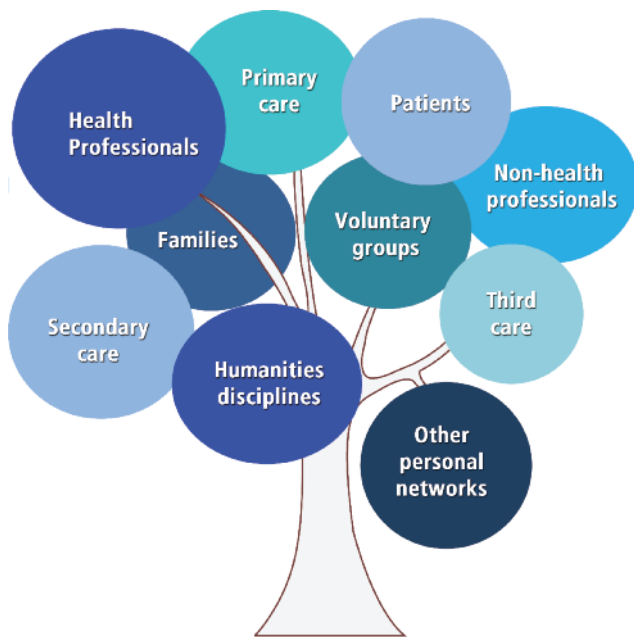
Projects on the European scale

It is well known that European projects are in an advantageous position to inform health policy, so this change of culture needs to start by proposing research projects which include European interventions looking at this holistic perspective of what living with a chronic illness means to a person and at how different agents need to collaborate to help people keep a balance between their illness and health.

In line with this idea the EU-WISE project takes a 'whole system approach' and aims to offer a deeper understanding of the processes involved in the day-to-day management of chronic conditions. This is a good example of how further understanding of chronic illness and everyday life could be developed. Connections between self-management and long term conditions could be delineated, establishing the mechanisms that link different aspects of support for chronic illness such as individual self-care, the involvement of social networks, and the contributions of voluntary, community and local organisations, as well as non-health and health professionals. Within the EU-WISE project an intervention (EUGENIE) has been designed based on previous data collected across Europe and piloted in six European countries.⁵

EUGENIE involves personal community mapping and analysis for people with long term conditions and looks at personal community and individual needs, links to tailored resources, patient-centred information and inter-organisational networks.

This comprehensive approach is essential if we, as researchers, policy makers and professionals from different disciplines and different levels of care, are to promote a better integration of chronic illness and people's life choices, and empower patients



and families in this long term journey. Therefore, patients and families could take control of the long term condition and be change agents in the team.

Sharing the illness experience

Moreover, as the EU-WISE project has investigated, bottom-up initiatives involving networks of lay people who share the illness experience are emerging in practice as a strong resource. A good example of these networks could be the voluntary organisations or associations of patients/families. These organisations are recognised as being important for the promotion of quality of life and are seen as an element in the range of services available to support the health and wellbeing agenda within local and national contexts.^{6,7,8} In addition, belonging to a group where people with long term conditions can share their own experiences can help people normalise the challenges they face.

In response to this new trend I would like readers to reflect on two main questions: 1) Are political and policy imperatives, such as patient empowerment and improvement in resource use, only rhetoric?; and 2) Are the voluntary sector and families taking over responsibilities from formal services which should be included in the health policy agenda?

Sustainability of outcomes in research programmes could be favoured by the development of health policies that ideologically and financially support intersectoral action and research with the involvement of government sectors, formal organisations, professionals from different disciplines and levels of care, and non-governmental players, including informal community groups, patients and their families.

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