

Health services research / Policy and plans

Review and analysis of the Spanish regulations on health and social care of people with neurodegenerative diseases and their families

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Salamanca, Spain.Email: evagonz@usal.es**Abstract**

Background: Neurodegenerative diseases (ND) constitute a problem of great magnitude, seriousness and complexity that require actions in the diverse areas of the Health and Social System (Ministerio de Sanidad, Servicios Sociales e Igualdad, 2016). These actions must cover the basic needs of patients and their families, while improving their care and quality of life. Given this situation, the aim of this study is to carry out a detailed review of the current national and regional regulations regarding health and social care of people with ND and their families.

Method: After a systematic review of 102 regulatory measures in Spain and in the Autonomous Community of Castile and Leon, those failing to consider the family of the person with ND were discarded. Finally, 35 instructions related to ND in terms of health and social services were analyzed and classified according to their scope (9 state regulations, 16 autonomous community regulations and 10 approved strategies).

Result: The analyses showed that: (1) only 34% of the regulatory instructions include contents that are directly or indirectly related to the quality of life of the families of these patients; (2) analyzed instructions do not specify how to coordinate resources and services in the health and social welfare sector for the care of people with ND and their families.

Conclusion: This study shows the lack of regulations in our region and country that specifically focus on the families of people with ND, as these relatives are not deemed to be direct beneficiaries. Likewise, there is a lack of specificity regarding the coordination of the services and resources for patients and their families. Reference: Ministerio de Sanidad, Servicios Sociales e Igualdad. (2016). Estrategia en Enfermedades Neurodegenerativas del Sistema Nacional de Salud. Madrid: Ministerio de Sanidad, Servicios Sociales e Igualdad.