Development of the Andalusian Registry of Patients Receiving Community Case Management, for the follow-up of people with complex chronic diseases

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Background: Complex chronic diseases are a challenge for the current configuration of health services. Case management is a service frequently provided for people with chronic conditions and despite its effectiveness in many outcomes, such as mortality or readmissions, uncertainty remains about the most effective form of team organization, structures, and the nature of the interventions. Many processes and outcomes of case management for people with complex chronic conditions cannot be addressed with the information provided by electronic clinical records. Registries are frequently used to deal with this weakness. The aim of this study was to generate a registry-based information system of patients receiving case management to identify their clinical characteristics, their context of care, events identified during their follow-up, interventions developed by case managers, and services used.

Methods and design: The study was divided into three phases, covering the detection of the needs, the design and its implementation in the healthcare system, using literature review and expert consensus methods to select variables that would be included in the registry.

Objective: To describe the essential characteristics of the provision of care to people who receive case management (structure, process and outcomes), with special emphasis on those with complex chronic diseases.

Study population: Patients from any District of PH-CSA, who initiate the utilization of case management services, is to provide information that may occur when including subjects who have already been receiving the service, and whose outcomes and characteristics could be properly collected.

Results: A total of 102 variables representing structure, processes and outcomes of care management were selected for their inclusion in the registry after the consensus phase (fig. 1). Total sample was composed of 427 patients, of which 511 (49.4%) were women and 316 (50.6%) were men. The average functional level (Barthel Index) was 36.1% (SD 29.03), cognitive function (Pfeiffer) showed an average of 43.7% (SD 6.57), Charlson Comorbidity Index, obtained a mean of 3.03 (SD 2.7), and Social Support (Duke Index) was 34.2% (SD 17.5%). More than half of patients included in the Registry, correspond to immobilized or transitional care for patients discharged from hospital (65.5%). The patient's educational level was low or very low (50.4%). Caregivers overestimate caregiver stress index), obtained an average value of 0.99% (SD 0.25). Only 1.2% of patients had declared their advanced directives. 53.6% had not defined the type of care and the vast majority lived at home 98.9%. Regarding the main events occurred at RANGE Registry, 28.8% of the selected patients died in the first three months, 8.2% suffered a hospital admission at least once time, 23% two times, and 1.2% three times, 7.5% suffered a fall, 8.7% had pressure ulcers, 4.7% had problems with medication and 3.3% were institutionalized. Stroke is the most prevalent health problems recorded (25.5%), followed by hypertension (11.1%) and COPD (11.1%). Patients registry by NCM, had as main processes, diabetes (16.5%) and dementia (11.3%).

The most frequent nursing diagnoses referred to the self-care deficit in various activities of daily living. Regarding to nursing interventions, described by the Nursing Intervention Classification (NIC), dementia management is the most used intervention, followed by mutual goal setting, caregiver and emotional support.

Conclusions: The patient profile who receive case management services is a chronic complex patient with severe dependence, cognitive impairment, normal social support, low educational level, health problems like stroke, hypertension or COPD and processes like diabetes or dementia, and has an informal caregivers. At the first follow-up, our patients had 19.2% of mortality, 10.3% of readmissions and 10.1% of falls.

Keywords: Case management, chronic disease, registry, electronic health records, health information systems, health care evaluation.