

Networks for caring for the needs of people with advanced chronic illnesses and at the end-of-life

Abstract

Introduction

This study is part of the project “All with you” (“Todos Contigo” in Spanish) – a social mobilization project that seeks to involve citizens and the society in general in supporting and caring people with advanced chronic illnesses at the end-of-life. It seeks to identify the needs of these people, as well as detect the ample network of citizens involved in facilitating the care for these people during the illness process. Such community involvement in the act of caring aligns with the other circles of care (Abel et al. 2013) – health and social care – in order to provide a fully integrated and efficient response.

Method

- Retrospective, observational study of a sample of people with advanced, terminal illness that were being cared for by the palliative care team of Badajoz. An aleatory sample of the total number of patients included in the palliative care programme was selected. The data gathering period was 5 months. As inclusion criteria, in addition to being in the palliative care program, a named-carer should be identified, who also should have accepted participating in the research through informed consent.

- Study variables included: patient and care network characterization, patient needs, carer's tasks. Batherl scales for measuring basic daily activities and the Lawton and Brody Scales were used. Additional clinical variables included: company support, case management, outpatient visit requests, A&E visits, decision making, etc. Support variables included: information and communication management, participation in activities to entertain patients, etc.

- Case assessments were made: at the inclusion of the patient in the study (v0), 15 days later (v1), 30 days later (v2) and 45 days later (v3). At each assessment, it was registered the current location of the patient and the existence of any unexpected event such as relapses, inpatient stays, A&E visits, etc.

- The study was authorized by the Clinical Research Committee of Badajoz

Results

Data for 112 patients have been gathered. An average of 5 people made up the network of care of each of these patients. A descriptive statistical analysis has been performed on the variables related to the needs of the patients and the profiles of carers involved. The results are shown through measures of central tendency, frequencies, and lineal regression for each variable and for each assessment until the death of the patient. A descriptive comparative analysis of needs that have been covered by carers has also been performed. Results will be presented at the ICIC16.

Conclusion

- The Network for Care and support for people from the community allows to fulfil the act of integrated caring for others at the end-of-life
- The study will reveal how the community cares for end-of-life people. It will train people to know how to look after other people, facilitating tools, liaising people willing to care with people needing care, developing a "network of care"
- This project is being replicated in Buenos Aires (Argentina) and Medellin (Colombia), using a multi-centric approach that helps identify networks of care in other countries which are also part of the "Todos Contigo" project.
- Results will allow designing a basket of services for supporting and caring for the complex needs of carers who look after patients with advanced, end-of-life illness.

Location

Spain

Year

2016

Related Integrated Care keywords

- PATIENT EDUCATION
- PERSONALISED CARE
- PERSON-CENTRED
- SERVICE, FUNCTION AND CARE INTEGRATION / COORDINATION – TRANSITIONS

Pervasiveness

Small scale in a local jurisdiction (multiple local jurisdictions)

Status

Ongoing

Links

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