

## ***Abstract for submission to Brussels Symposium, September 2016***

### **What are the fears and support needs of those living alone in the last year of life and who responds?**

Sean Hughes, Nancy Preston, Sandra Varey, Sheila Payne, Marlieke van der Eerden, Sven Schwabe, Csilla Busa, Karen Van Beek, Suzy Van Ende, Agnes Csikos, Marieke Groot

#### **Background**

There is a general assumption that family caregivers will be available and willing to provide support to those living with terminal illness in the last year of life; but what of those who live alone at this time? Others<sup>1</sup> have highlighted the need for patients in this situation to develop trusting relationships with their professional caregiving network and with key professionals in particular. This can enable sensitive discussion and planning about future care wishes – a clear necessity as disease progresses.

#### **Design and methods**

Patients with advanced cancer, COPD and chronic heart failure (CHF), with a prognosis of less than 12 months, were recruited at clinical services sites in five European nations: Belgium, Germany, Hungary, The Netherlands and the United Kingdom. Data were collected using semi-structured interviews at baseline and at three months follow-up. Quantitative data were collected using POS, CANHELP Lite tools at monthly intervals and in weekly self-completed patient 'diaries'. Interviews focused on how integrated palliative care services responded to patients' needs and problems. A transnational comparative analysis was conducted using a qualitative thematic approach.

#### **Results**

Of 157 patient participants, 48 (30%) lived alone (range by country: 13%-41%). Of this sub-sample, the mean age was 73 years and 58% were women. Diagnoses were: cancer ( $n=27$ ), COPD ( $n=13$ ), CHF ( $n=7$ ), not recorded ( $n=1$ ). Many patients reported being fearful about the future; feeling lonely and isolated; feeling a burden on others; and problems with 'the little things'. Conversely, many were able to give examples of where individual professionals and services responded to their needs quickly and with sensitivity. Informal sources of support from neighbours and friends were apparent and included practical help, emotional assistance and social engagement.

#### **Conclusion**

Commonalities across the participating nations in the fears and concerns of patients living alone in the last year of life were apparent. However, there was variability in how services responded to needs and in the extent to which these responses were integrated and coordinated. Lone patients are a potentially unrecognised sub-group with a particular set of needs in relation to professional engagement. Integrated palliative care services need to acknowledge this and respond accordingly. Further research into how palliative care service provision towards the end of life dovetails with informal support networks is required.

1. Hanratty et al. (2013). What is different about living alone with cancer in older age? A qualitative study of experiences and preferences for care. *BMC Family Practice*. 14:22. <http://www.biomedcentral.com/1471-2296/14/22>

On behalf of InSupC: EU FP7 funded project (Ref: 305555) on integrated palliative care in Europe