

CONFERENCE ABSTRACT

Person-centred palliative care in five European countries: the experiences of patients and family carers

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Introduction: Integrated palliative care (IPC) should be responsive to patients' palliative care needs. However, knowledge about the best way to provide IPC is scarce. Evidence is mainly based on perspectives of professionals and carers. Therefore, the InSup-C project conducted a qualitative study on the experiences of patients' and their carers' with care provision in several IPC initiatives in five European countries. The aim of this study was to examine how IPC initiatives respond to patients' problems and needs.

Methods: IPC initiatives, i.e. cross-sector collaborations between professionals to provide palliative care, were recruited in five European countries (Belgium, Germany, Hungary, The Netherlands and the UK) between June 2014 and August 2015. From these initiatives patients with cancer, COPD and Chronic Heart failure (CHF) with a prognosis less than 12 months and their carers were recruited. Semi-structured interviews were conducted at baseline and after 3 months using uniform interview protocols. Interview protocols focused on patients' problems and needs, identification of professionals in patients' care networks, quality of relationships with professionals and inter-professional collaboration. Interviews were transcribed verbatim. Transcriptions were coded using an internationally agreed codebook based on a qualitative thematic approach.

Results: Hundred and seventy-five patients and 90 family carers were interviewed. Of 157 patients, 10% were from Belgium, 22% were from Germany, 22% were from the United Kingdom, 27% were from Hungary and 20% were from the Netherlands. Regarding diagnostic group, 62% had cancer, 13% had CHF and 25% had COPD. Mean age was 67 years and 55% were female.

Of 90 family caregivers, 17% were from Belgium, 11% were from Germany, 14% were from the United Kingdom, 33% were from Hungary and 24% were from the Netherlands. Mean age was 59 years and 68% were female.

The following four themes emerged from the data and related to person-centred care:

- Compassionate care: Patients and carers valued professionals who saw the person beyond the illness and who were involved with them. This enabled a personal relationship and care that was being tailored to patient's holistic problems and needs.

- Patient-centred information: Patients and carers found it important that professionals were honest in giving information about prognosis and treatment possibilities and were patient in their explanation. This allowed patients and carers to ask questions and give their opinions. Patient-centred information provided trust and support in times of uncertainty.

- Availability of caregivers: Patients and carers appreciated professionals who 'were there' for them, that they knew who to contact in case of needs and that professionals responded adequately when it was necessary.

- Inter-professional collaboration: Patients and carers found it important that professionals transferred information and consulted each other when necessary. This resulted in professionals who were up-to-date about the patient and prevented them from telling their story over and over again. It also gave them a sense of trust when they experienced that professionals in their network looked after them together.

When the four themes were available in care provision patients and carers were satisfied about care received. Many examples of person-centred care were reported, resulting in patients and carers who experienced care provision as a safety net of professionals who feel responsible and work together in order to adequately respond to their palliative care needs. In cases where these components were absent or insufficiently present, it sometimes resulted in unmet needs, uncertainty or dissatisfaction. Indeed, examples of professionals who only focused on the illness instead of seeing patients as a person or who did not collaborate properly were also reported. Frequent complaints were based on a lack information transfer in the professional-patient and/or professional-professional relationship. Although not always desirable, instances of patients or family caregivers who actively transferred information between professionals themselves were reported. In some cases, assertiveness of patients or carers concerning their dissatisfaction lead to improved care experiences. Country specific differences were found regarding availability of medicines, the role of hospices and main professionals.

Discussion and conclusion: These results provide valuable insight in the aspects that are deemed important by patients and their carers from five European countries in order to realise person-centred integrated palliative care. These will contribute to the improvement of integrated palliative care in Europe and will therefore be interesting for both clinicians and policy makers who are involved in this field.

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van der Eerden; Person-centred palliative care in five European countries: the experiences of patients and family carers.

Keywords: person-centred care; integrated palliative care; patient experiences
