Conference Abstract

Patient-centered integrated palliative care pathways in advanced disease: a mixed methods study

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Abstract

Introduction: People with life threatening disease across Europe face challenges in engaging with a wide range of agencies and multiple professionals during the course of their illness, even up to the point of death. It is known that many services attempt – formally or otherwise – to dovetail their efforts with others in the local health economy, but little is known about these initiatives, nor about what works best in terms of service organisation. This is especially the case when considered from the patient and carer standpoint. Against a backdrop of shrinking resources for health and social care in an age of austerity and in the light of an ageing population with increasing need, more needs to be known about how integrating aspects of service delivery will best help people in the last phase of their lives.

Study design: The study will use a mix of quantitative and qualitative approaches to investigate integrated palliative care pathways in advanced cancer and chronic disease.

Methods: The study will be conducted by an international team in five distinct phases:
1. Systematic review of the literature considering existing evidence for integrated palliative care initiatives in Europe
2. Development of a taxonomy of integrated palliative care initiatives in Europe
3. Data collection exploring the experiences of patients, carers and professional care givers of integrated palliative care initiatives in five European nations using shadowing techniques, qualitative interviewing and quantitative quality of life and symptom burden measures
4. Development of (requirements for) best practices in integrated palliative care in Europe based on the analysis of gathered data
5. Development of an elearning platform around best practice in integrated palliative care aimed at equipping professionals with knowledge to enhance and influence local care provision

Dissemination: Study outputs will be disseminated throughout the project using a variety of methods including: scientific publications and presentations; the provision of an interactive website; the development of an elearning platform; engagement with social media and ending with an invitational conference aimed at influencing policy development at senior European political and policy decision making level.
**Conclusion:** Our knowledge about integrated palliative care pathways in advanced disease remains patchy and incomplete. It is clear that many initiatives are underway across Europe. Our study will pull together that knowledge, enhancing it significantly with the views of patients and those at the coalface of service delivery, putting us in a position to make evidence based recommendations for best practice in this field.

**Lessons Learned:** Our knowledge about which models of integrated palliative care work best is incomplete. Understanding the patient and carer experience of integrated care models from their standpoint is critical. Investigating integrated palliative care models across national boundaries will allow for different and novel approaches to be compared.

**Keywords**

integrated care, palliative care, advanced disease, care pathways

**Powerpoint presentation:**

http://www.integratedcarefoundation.org/content/new-research-integrated-care