

Advanced Illness and Changing Needs symposium

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The Advanced Illness and Changing Needs symposium was held on 30 April 2015 at the Royal College of Physicians of Edinburgh

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INTRODUCTION

Healthcare professionals from all specialties recognise the changing landscape of our patients and society. The complexity of an ageing population with multimorbidity poses a major challenge, and palliative care will play a key role in meeting the needs of these patients. Identification, communication and collaboration are key themes in planning for the future, which were reflected in the symposium. Speakers and attendees from a range of disciplines provided a fascinating and inspiring programme, underpinned by innovation and evidence.

SESSION 1: HOW CAN EARLIER IDENTIFICATION IMPROVE OUTCOMES FOR PEOPLE WITH ADVANCED ILLNESS AND CHANGING NEEDS?

Dr Boyd (Royal Infirmary Edinburgh) opened the session describing the development of the Supportive and Palliative Care Indicators Tool (SPICT).¹ SPICT is a simple, open-access tool with robust, readily identifiable 'clinical indicators' for use by a range of healthcare professionals to support clinical judgment and provide early holistic care. Timely identification of patients with long-term conditions is fundamental in supporting them in living well while managing uncertainty. The SPICT community continues to grow internationally and is highly rated professionally.

Dr Chaitanya (Royal Derby Hospital) presented the AMBER care bundle. AMBER provides a systematic approach to support the care of hospital patients who are at risk of dying in the next 1–2 months. Care of 555 patients was supported with the bundle in the first year and medical readmissions reduced from 17% to 7.5%. Preferred place of death was achieved in 85% of patients. Quality of discharge communication is a key

part of supporting primary care in the community. The improved outcomes relating to components of care within the AMBER bundle were sustained after two years, and the challenge now is to produce a robust evidence base for the tool.

Professor Taylor (University of Edinburgh) illustrated the challenges encountered in acute medical care including discontinuity and protocol-driven interventions, and emphasised the need to accept death. The Lanarkshire 'Ceiling of Treatment' tool aims to avoid inappropriate interventions for patients who are deteriorating and improve communication and decision-making out of hours. Of staff in clinical areas using the tool, 92% felt it had a positive impact on patient care. The tool does not give specific guidance on withdrawal of treatment. Professor Taylor stressed the importance of common sense, compassion and communication.

SESSION 2: INTEGRATED CARE FOR PEOPLE WITH ADVANCED NEUROLOGICAL CONDITIONS

Dr Gorrie (Southern General Hospital, Edinburgh) provided practical advice in challenging areas of symptom control for patients with motor neurone disease.² Gastrostomy is an option for nutritional support although there is no survival benefit, while non-invasive ventilation provides a survival benefit of 216 days compared to 11 days with best supportive care. Botox is a potential option for excess saliva and improves quality of life. Throughout the presentation, the perspective of the patient was heard via pre-recorded video interviews. Symptom control and timely decision making is a key part of supporting patients with motor neurone disease to ensure quality of life is preserved.

A case-based discussion led by Mr Stockton (Motor Neurone Disease, Scotland), gave the audience an opportunity to challenge themselves with issues of diagnosis in primary care, prognostication, carer stress, assisted suicide and providing end of life care. All these were tackled with knowledge and support from the expert multi-disciplinary panel.

SESSION 3: EVIDENCE-BASED PRACTICE IMPROVES PALLIATIVE CARE FOR ALL

The John Hamilton Brown lecture, delivered by Dr Jackson (Harvard Medical School), presented the concept of cultivating prognostic awareness in patients with cancer. Prognostic awareness gives the patient insight into their illness journey and allows them to make decisions about treatment, have meaningful discussions and match treatment decisions to personal goals. A framework that focuses on living, while tolerating the possibility of dying is helpful. Communication with patients is paramount, and understanding that patients communicate with different health professionals in different ways helps build an understanding of the patient's values and improves collaboration between oncologists and palliative care specialists.³

The Scottish Palliative Care Guidelines⁴ were released by Healthcare Improvement Scotland in December 2014. Dr Gray and Dr Baughan (National Palliative Care Guidelines Group Chairs) gave us a practical overview of their application in clinical practice. They were developed by a multidisciplinary group of professionals working in the community, hospitals and specialist palliative care services. Focus groups with carers and members of the public were also part of the process. They are designed for health professionals from any care setting. An NES education module and app will be released soon to support use of the Guidelines.

SESSION 4: WORKING IN PARTNERSHIPS

Professor George (Cicely Saunders Institute, London) encouraged an ethical perspective when considering best interest decisions. The law provides frameworks when using substituted decision-making, although the challenge of contemplating our future selves was richly illustrated through recitation of the Seven Ages of Man. Autonomy is necessarily limited by others in practice. The 'Priorities for care of the dying' are a clear statement of our professional responsibilities and the five key principles were outlined: recognise, communicate, involve, support, plan and do.

The Rev Dr Kelly (NHS Dumfries and Galloway) delivered an emotive lecture about human relationships

and emphasised the importance of knowing our own needs, and connecting with humanity.⁵ Value based reflective practice is a model that promotes reflexivity and enhance person-centred practice. NAVVY is a useful tool that asks questions relating to five dimensions of practice: **needs, abilities/capabilities, voices, values** and what does a situation reveal about you, me and us.

Mr McEvoy (North Tees University Hospital) described the Family's Voice diary, an action research project that has seen 501 diaries completed since 2011. The diary engages staff and families in sharing the care of dying patients by providing a questionnaire that the families complete daily. Its use appears to reduce complaints and support families. A multi-centered trial of the Family's Voice diary is ongoing.

CONCLUSION

We encounter increasing numbers of patients with advanced, progressive conditions and frailty every day, in primary and secondary care. At this symposium, the speakers' breadth of knowledge and experience proved inspirational, while the content provided a mixture of pragmatic tools and personal accounts to encourage reflection in clinical practice. The patients' story was present throughout the day in many forms and as we continue to strive to meet the challenge of our changing society, we should listen carefully for our patients' voices in our noisy working lives.

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