

Winter 2018

CSINews

news from cicely saunders international

Cicely Saunders
International
Better care at the end of life



Just read this edition of CSI News and see why I, as a trustee of CS International from its early beginnings, am so honored to be a witness to their enormous progress in advancing the evidence base for palliative care nationally in the UK and globally.

Embracing the concept of palliative care as a public health and human rights issue, CS International has created a center of excellence of multidisciplinary researchers asking challenging questions that serve to create a framework for model care delivery with the tools and methods to assess interventions and implementation strategies.

At a recent research review day for external experts and trustees, the range of work in progress at the Institute was breathtaking and the publication output outstanding. Two recently published Lancet Commission Reports addressing the need for palliative care have identified research priorities that position CSI as never more relevant and important.

CSI News captures how much the Institute's work emulates Cicely's call to set priorities based on patient preferences. CSI has clearly positioned itself to lead on a robust collaborative national and global research and educational agenda to inform the multiple actors who can decide how to make hospice and palliative care a priority for all.



Dr Kathleen Foley

Trustee, Cicely Saunders International

*Commitment to openness,
openness to challenge
and the absolute priority
of patients' own views
on what they need.*

Dame Cicely Saunders



Healthcare system must adapt to rising pressures on emergency services

Pressure on emergency services is increasing. Researchers at the Cicely Saunders Institute have published research showing the number of emergency hospital admissions for people in their last year of life could increase by 85% to 2.8 million by 2041, placing significant strain on the National Health Service.

In a letter published in *The Lancet* researchers examined the impact of population ageing on end of life care in NHS hospital and community services. They projected future trends in emergency admissions for people in their last year of life.

If admissions continue to rise at current rates, the number of hospital admissions each year will almost double, increasing by more than 1.3 million, to 2.8 million by 2041.

Author Anna Bone from the Cicely Saunders Institute said: *“Most people state that they prefer home-based or home-like care with access to out-of-hours care. Multiple trips to hospital in the months before death can be distressing for both patient and family, and is costly for the health system.*

“We need to adapt to this new era of patient and family needs, and find a sustainable way to provide quality care towards the end of life. The system needs to respond quickly to meet needs and provide care where people want to be cared for.”

Read the full letter here: <https://bit.ly/2POC1mj> DOI: 10.1016/S0140-6736(18)31823-3

RESEARCH NEWS:

Hospital palliative care is cost-effective and improves outcomes

A study led by Professor Charles Normand, Professor of Economics of Palliative Care & Rehabilitation at the Cicely Saunders Institute, analysed the association between palliative care consultation (PCC) and hospital costs for adult inpatients.

It found that not only is PCC associated with lower costs (per previous studies) but that systematic associations are observable between baseline clinical factors and cost-saving estimates. In particular, PCC appears most impactful on patterns of treatment for those with high numbers of comorbidities – i.e. the population who account disproportionately for health care costs yet experience poor outcomes. Palliative care could therefore be a critical tool for policymakers looking to improve outcomes and curb cost growth among those with serious illness in an era of demographic ageing.



May P, Normand C, Cassel JB, Del Fabbro E, Fine RL, Menz R, Morrison CA, Penrod JD, Robinson C, Morrison RS. **Economics of Palliative Care for Hospitalized Adults With Serious Illness: A Meta-analysis.** JAMA internal medicine 2018; 10.1001/jamainternmed.2018.0750.

COALITION NEWS:

The NHS Long Term Plan



The UK government is consulting on the long term plan for the NHS. The Cicely Saunders Institute has issued the following statement:

Strong evidence, from the UK and beyond, shows that palliative care is a high value intervention: it improves outcomes for patients and families, at the same or lower overall costs, particularly for people who have the most complex needs.

Our population is ageing, and people are increasingly living with multiple long-term conditions and frailty. Integrated care is needed to deliver appropriate and coordinated services, at the right time and in the right place, according to patients' individual needs and those close to them.

But spending on palliative care in England is highly variable. Some clinical commissioning groups spend as little as £52 per person per year on palliative care. Health economic analyses show that providing palliative care can save costs overall, particularly when provided early.

For the NHS Long Term Plan to be effective, palliative care must be included within models of integrated care for people living with advanced disease and multimorbidity. This will require investment in multi-professional expert palliative care teams in hospitals and the community, working in new and integrated ways with others. There is a strong argument for supporting local demonstration projects to identify the best ways to do this.

Read the full statement here: <https://bit.ly/2y74k7T>

Global health news

The Global Health Centre at the Cicely Saunders Institute leads global programmes and supports local initiatives by providing data analysis and statistical support to collaborating partners.

Current programmes include strengthening health systems in Africa, building healthcare capacity in conflict regions in the Middle East, and working with the World Health Organization to pilot use of an app to allow self reporting of POS (Palliative care Outcome Scores) in India and Africa.

Capacity building initiatives currently include:

- Uganda (TB)
- Ghana (burns)
- Nigeria (Renal)
- India (Stigma in HIV and Cancer)
- Zimbabwe (Bereavement)

The Global Health Centre is also developing the C-POS (Palliative care Outcome Scale for Children) for worldwide use, and researching childhood bereavement.

Work on self-management of pain in HIV in Africa has led to the recent award of a UK NIHR grant to translate the intervention for use in the UK. The Centre is also developing NIHR guidance for the UK NHS on LGBT communication in serious illness.



GLOBAL HEALTH NEWS:

Palliative care needs of refugees in Jordan

Professor Richard Harding, Director of the Centre for Global Health Palliative Care at the Cicely Saunders Institute, and Dr Omar Shamieh (Local Principal Investigator), Director of the Center for Palliative & Cancer Care in Conflict (CPCCC), King Hussein Cancer Center, Amman, Jordan have recently launched a Phase I study exploring the palliative needs and experiences of those with advanced cancer including refugees in Jordan.

This work is part of a large project funded by the Global Challenges Research Fund (GCRF) to build sustainable research capacity and capability for the health sector in countries in the Middle East and North Africa (MENA) impacted by conflict –

Research for Health in Conflict (R4HC-MENA). The focus is on generating robust evidence to advocate for better policies and practices, and working alongside partners to provide scientific support to address local priorities and challenges.

Responding to World Health Organization's End TB strategy

Tuberculosis illness is associated with uncertain outcomes and has high prevalence among people living with HIV. The new World Health Organization's End TB strategy specifies that person-centred symptom management and psychosocial support must be offered alongside standard medical treatment.

CSI researchers led by Dr Kennedy Nkoma looked at data collected from 400 adult patients with a confirmed HIV diagnosis attending HIV outpatient care in Kenya. 61 patients were on TB treatment. The team used the African Palliative Outcome Scale to assess patients' problems and concerns, controlling for demographic variables – age, gender, education, wealth – and clinical variables – stage of illness, HIV treatment status, TB treatment status, and CD4 (T-Cell) count.

Patients had low scores particularly with regard to being able to share their feelings, to have help and advice to plan for the future, to be at peace, being in pain and feeling that life was not worthwhile. HIV patients with TB had worse scores, particularly with regard to existential and spiritual well-being. Researchers highlighted the need for holistic symptom assessment and person-centred care to respond positively to the WHO's End TB strategy.



Palliative Care in Oman

Earlier this year researchers from the Cicely Saunders Institute attended the launch of a new palliative care initiative in the Sultanate of Oman. In Oman, palliative care is still in its infancy. Many acute hospital beds have patients who would benefit from palliative care to improve their quality of life.

Palliative care has an important role to play in the care of the elderly and particularly patients with dementia and Alzheimer's Disease. As the ageing population of Oman grows, there will also be increasing demand for health care services that meet the needs of older people with these and other complex conditions.

Dr Al Mandari, a senior oncologist said:

"Palliative care is not just for cancer patients. It's not about diagnosis: it's about need and particularly, pain control. It may include rehabilitation and curative options and must always be tailored to the needs of the individual."

Professor Richard Harding from the Centre for Global Health Palliative Care, at the Cicely Saunders Institute said:

"The emphasis must always be on providing quality care and measuring outcomes. In Oman there will also need to be some changes in legislation relating to the availability of opioids used for pain control and place of death to allow patients to be treated more easily within the community."

Dr Richard Harding and Minister for Health, Dr Ahmed Al Saudi.



CONGRATULATIONS:



Professor Lynne Turner-Stokes

Congratulations to Professor Lynne Turner-Stokes who has been awarded the Royal College of Physicians President's Medal for Services to Specialist Medicine in Areas with Wider Application.

Lynne was appointed to the Herbert Dunhill Chair of Rehabilitation at King's in 2001, with a view to developing a two-site academic department of rehabilitation between King's and Northwick Park Hospital. Academic Rehabilitation joined forces with the Department of Palliative Care and Policy in 2003, now at the Cicely Saunders Institute.

Northwick Park's Regional Hyperacute Rehabilitation Unit provides a tertiary specialist rehabilitation service for younger adult patients with severe complex disabilities, mainly resulting from acquired brain injury. The RRU acts as a central focus for research and training for all professionals involved in rehabilitation, and has a national and international reputation as a leading service in the field of neurological rehabilitation.

Professor Turner-Stokes' latest scientific paper, co-authored by Dr Mendy Dzingina, Lecturer at the Cicely Saunders Institute, is due to be published shortly in the Journal of Head Trauma Rehabilitation. The paper is about life-time savings from rehabilitation following traumatic brain injury. The findings demonstrate lifetime savings in excess of £4.1bn for the national cohort of patients with severe traumatic brain injury admitted for specialist in-patient rehabilitation in England, making rehabilitation one of the most cost-effective interventions in healthcare.

CONGRATULATIONS:



Marsha Dawkins

Congratulations to CSI Clinical Nurse Specialist Marsha Dawkins who has been awarded a pre-doctoral clinical academic fellowship by the NIHR. Pre-doctoral Clinical Academic Fellowships fund personalised programmes of academic training to give trainees the skills and experience to access doctoral level funding, alongside providing clinical care to patients and families.

Since 2014 Marsha has been working with several NHS acute trusts and hospices across the UK to support the implementation of a validated set of outcome measures into routine clinical practice.

Palliative care outcome measures are used by clinicians to systematically record information about their patients' symptoms and concerns. The data is reviewed and monitored over time to ensure that patients receive the best possible symptom control and psychosocial support.

Marsha has also been researching the implementation process, and how outcomes data may best be used.

Marsha will develop group-based learning methods and set up a learning collaborative to promote knowledge-sharing across palliative and end of life care services. She will investigate how patient level data is used for quality improvement, to inform clinical care and support funding decision-making with practitioners, patients and their representatives and commissioners.

Clinicians, stakeholders and policy-makers visit from Bavaria

In October the Cicely Saunders Institute welcomed a group of visitors from Bavaria in Germany. The group of 30 clinicians, stakeholders and policy-makers was led by Claudia Bausewein, a former CS International scholar who is now Professor of Palliative Medicine at the University of Munich.

The aim of the visit was to bring together people from Bavaria in leading positions (including the Ministry of Health) to visit hospice and palliative care institutions in London to get new ideas and

inspiration for developing hospice and palliative care in Bavaria. In addition to visiting the Institute, the group also visited St Joseph's Hospice in Hackney and St Christopher's Hospice in Sydenham.

EVENT:

Inaugural lecture

6 December 2018

Cicely Saunders Institute, Denmark Hill Campus, London SE5

Inaugural lectures are an opportunity for our Professors to introduce themselves and their work. Their lectures present an overview of their own contribution to their field as well as highlight the latest developments in their discipline to an audience consisting of both members of the university and the wider public.

The lectures will be followed by a reception showcasing research posters from across the faculty. As well as being a great networking occasion for our research community, it is an opportunity for visitors to meet our researchers and find out more about how their work is improving people's lives and healthcare systems around the world.

Academic rehabilitation: a road less travelled

*Professor Lynne Turner-Stokes,
Northwick Park Chair of Rehabilitation Medicine*

Establishing an evidence-base for the effectiveness and cost-efficiency of rehabilitation has been a key ambition of Lynne's career. Her talk will chart her 15-year journey to achieve this, highlighting the interesting and productive partnership which arose between rehabilitation and palliative care.

Achieving equality at the end of life: the emergence of global health palliative care

Professor Richard Harding, Herbert Dunhill Chair

Richard will chart the development of this branch of research in global health palliative care. The development and implementation of robust outcome measures have generated an evidence-base of need and effectiveness. Once embedded into routine practice, outcome measures drive up quality of care.

To register please visit <https://bit.ly/2DbsIKq>



Centenary Celebrations 2018

Cicely Saunders
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The Cicely Saunders Institute will be hosting a series of events in 2018 celebrating the centenary of Cicely Saunders.

The events will include seminars, workshops, music, film and talks.

Contact csi.events@kcl.ac.uk for more details and follow us on Twitter @[cicelysaunders1](#) and @[csi_kcl](#) #[Cicely100](#)

Celebrating in partnership with



EVENT:

Health, till death do us part? Impact of spousal bereavement on health and mortality among older adults in Sweden

28 November 2018, 16:00 to 17:00
Cicely Saunders Institute,
Denmark Hill Campus, London SE5

Speaker: Lucas Morin, PhD Training Fellow at the Aging Research Center of Karolinska Institutet in Stockholm (Sweden).

Before joining Karolinska Institutet, Lucas was the director of the French National Observatory on End-of-Life Care in Paris, France. He will present the results of recent research showing significant and rapid impact on both fatal and non-fatal health outcomes among surviving spouses.

EVENT:

Outcome measures in palliative care: using the POS family of measures

7-8 February 2019
Cicely Saunders Institute,
Denmark Hill Campus, London SE5

These workshops introduce and support the use of the POS family of measures in clinical, research and care settings. The event is for all professionals (nurses, doctors, physiotherapists, psychologists, occupational therapists, social workers, managers, allied professionals, commissioners and researchers) with an interest in palliative and end-of-life care. Each year this event brings together professionals in palliative care and gives them an opportunity to hear about innovative approaches and latest developments, essentials of administration, integration, scoring, validation, data capture and interpretation with the POS family of measures.

To register please visit <https://bit.ly/2EtHg9z>

Cicely Saunders International is a registered charity 1087195. It relies entirely on charitable support to carry out its programme of world class research and education. If you would like to make a donation please contact sian.best@cicelysaundersinternational.org or visit our website cicelysaundersinternational.org

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