

6th Annual Research Conference

- **Keynote Professor Afaf Girgis**
- **Palliative Care Clinical Trials Collaborative**
- **Abstract Presentations**

In this edition of Centre Line we focus on our recent Research Conference, held in Brisbane on 25 May, 2007.



Keynote by Professor Afaf Girgis

The keynote address at the conference was delivered by Professor Afaf Girgis, and looked at guidelines to improve the match between levels of need and utilisation of palliative care services.

REFERRAL GUIDELINES PROJECT Needs-based palliative care in Australia

Late referral, crisis referral, and in some instances non-referral of patients to specialist palliative care services (SPCS) impact significantly on the quality of life of patients and their carers. Uncertainty regarding when to refer and the reasons for referral are also common amongst the general health professional community. More recently however, there has been a growing recognition that palliative care services may be appropriate for a wider range of patients than has traditionally been the case.

Given the potential expected increase in the demand for SPCS, poor understanding of how and when to best refer patients, and the likelihood that resources will remain static at least in the foreseeable future, referral guidelines and screening tools are pivotal to facilitate equity of access to finite palliative care resources.

The introduction of the guidelines and tools is expected to reduce the incidence of late and crisis referral, and improve referral where psychological, social, physical and spiritual problems are evident. Improved outcomes for patients and families are expected to include improved symptom control, quality of life and satisfaction with care.

The following program of work should result in palliative care resources being allocated in a more systematic and objective way, on a transparent needs basis. This is in contrast with services currently being allocated in an ad hoc manner across the nation.

The following comprehensive program of work is expected to improve patient-centred care and need-based utilisation of SPC services in Australia. Phases 3-6 are funded by the Australian Government Department of Health and Ageing.

Phase 1: A large national qualitative study exploring perceptions of palliative care and issues surrounding referral in the Australian health care system. **COMPLETED**

Phase 2: A national survey of doctors to determine current referral practices, predictors of different referral patterns and the prevalence of triggers used to precipitate referral to palliative care. **COMPLETED**

Phase 3: Development of national patient-centred consensus SPC Needs Assessment Guidelines and a Palliative Care Needs Assessment Tool (PC-NAT), to enhance SPC resource utilisation and increase equitable access to SPC. **COMPLETED**

Phase 4: Evaluation of the impact of the guidelines and tools on patterns of palliative care (referral, utilisation and complexity of care) and on patient and carer outcomes. **UNDERWAY 2006-2008**

Phase 5: National dissemination of the guidelines and tools, with relevant training of referrers and palliative care services. **TO BE UNDERTAKEN IN 2009**

Phase 6: Generalising the resources to non-cancer palliative populations. **TO BE UNDERTAKEN IN 2009**

Professor Girgis described the process of development and pilot testing of the PC-NAT, and the anticipated roll out in 2009. Feedback on the tool has been very positive, especially regarding clarity and ease of use.

The members of the project team bring a balance of behavioural science, clinical and health system (including health economic) expertise to the proposed program of work. Furthermore, the members of the team are able to draw on national multi-disciplinary collaborative links to ensure the success of the program in meeting its objectives.

The program is managed through the Centre for Health Research & Psycho-oncology, based at The University of Newcastle and includes:

Professor Afaf Girgis

Centre for Health Research & Psycho-oncology, The Cancer Council NSW & The University of Newcastle, NSW

Professor David Currow

Flinders University, Adelaide, SA

Ms Claire Johnson & Ms Amy Waller

Centre for Health Research & Psycho-oncology, The Cancer Council NSW & The University of Newcastle

Professor Linda Kristjanson

Curtin University of Technology, WA

Professor Patsy Yates

Queensland University of Technology, QLD

A/Professor Geoff Mitchell

University of Queensland, QLD

Professor Brian Kelly

The University of Newcastle, NSW

Professor Martin Tattersall

University of Sydney, NSW

Dr Amanda Neil

Consultant, QLD

Dr David Sibbritt

The University of Newcastle, NSW

Enquiries:

Senior Project Officer, Ms Claire Johnson

P: 02 4924 6346 E: Claire.Johnson@newcastle.edu.au

Abstract Presentations

The clinical pathways presentations at the conference were very similar to those in the last edition of Centre Line. All presentations for which permission has been granted will be available on the CPCRE web site <www.cpcrc.com>.

Breakthrough breathlessness: is there a role for nebulised narcotics?

Dr Elizabeth Reymond (Director, Brisbane South Palliative Care Collaborative)

Breathlessness is a distressing symptom for palliative care patients, families and professional carers. Research is lacking in how to best manage this debilitating symptom. Recent studies indicate regular systemic narcotics are useful to relieve the perception of background breathlessness.

However little evidence exists concerning treatment of breakthrough, or acute episodic, breathlessness. This double-blind controlled cross-over study was designed to compare the effects of nebulised hydromorphone, systemic hydromorphone and nebulised saline for the relief of episodic breathlessness in advanced cancer patients.

Each of the treatments resulted in statistically significant improvements in breathlessness, but there were no significant differences between treatments.

The results suggest it is reasonable to trial nebulised saline rather than narcotics as a first line treatment for breakthrough breathlessness.

The use of pain scales in residential care for those who cannot verbalise

Deborah Parker, Senior Research Fellow, Dementia Collaborative Research Centre, Queensland University of Technology.

This paper reports results relating to use of pain scales in Australian Residential Aged Care Facilities (RACFs) for people unable to verbalise. In 2005, Australian Pain Society testing of the Abbey pain scale and the Pain Assessment IN Advanced Dementia scale (PAINAD) indicated both were reliable and valid instruments for this population.

Surveys were distributed to 2,523 RACFs throughout Australia. A total of 598 surveys (28%) were returned. The most commonly used pain assessment tools were the Abbey Pain Scale (65.4%) and Checklist of Non-Verbal Indicators (32.2%). The PAINAD was only used by 5% of respondents.

All questions for the Abbey scale were rated as helpful, in particular change in facial expression (90.6%), body language (88.3%) and behavioural change (88.3%).

Measuring reluctance to care: dilemmas, discoveries and directions

Letitia Burridge, School of Population Health, University of Queensland

This paper focused on an exploration of why it is important but difficult to measure reluctance to care (RTC), aspects of lay cancer carers' reluctance, and the implications of these findings.

RTC is increasingly relevant in the de-institutionalisation of care for chronic illnesses, including cancer. It is an unwelcome, under-developed and under-estimated concept. Potential indicators of RTC identified in a systematic review included a perceived lack of choice and disruption to lifestyle.

In general, spouses were more willing and motivated to care; non-spouses felt less choice about the role. Female

carers felt less choice than male carers, and found it more disruptive and stressful. Male carers felt less resentful than female carers about caregiving.

The results were limited by the extent to which the burden instrument measured RTC, carers' willingness to disclose their feelings, and the quality of the carer-patient relationship. Nonetheless, they suggest that RTC occurred, and that carers can feel simultaneously reluctant and committed. This creates a moral dilemma between respecting individual autonomy to take the role and protecting against caregiving adversity. With further clarification of the concept, a comprehensive measure of cancer RTC can be developed.

Management of sub-cutaneous medication administration in the home - Queensland lay caregivers' perspectives

Fiona Israel, Clinical Nurse Consultant – Research, Brisbane South Palliative Care Collaborative

Most palliative care patients prefer to be cared for at home. While promoting quality of life for patients, this preference impacts on their carers. Lay caregivers in Australia can be required to deliver and adjust complex medication regimes including subcutaneous (s/c) injections. This prospective qualitative study investigates caregivers' perceptions concerning injection of s/c medications in the home.

Fourteen carers were interviewed on two separate occasions, once during the care giving stage and again two months after the carer's bereavement. Interviews were based on a semi-structured schedule that attempted to explore whether carers regarded their medication provider role as a positive or negative experience. Interviews were digitally-recorded, transcribed verbatim and the text content analysed using QSR N6 software.

In the first interview, carers expressed anxieties associated with their ability to administer injections. Most had concerns regarding the processes associated with injecting and experienced fears of overdosing their family member. In the bereavement interview carers reflected being pleased they had contributed to the symptom relief of a family member. It appears that although carers would not necessarily volunteer to inject family members, they were generally empowered by the experience.

The data collected is necessary to inform a better understanding of the factors that influence outcomes in palliative caregiving. Development of that understanding will influence the design of interventions that support lay caregivers to successfully achieve their extended care giving role.

Palliative Care Clinical Trials Collaborative (PaCCSC)



Professor David Currow, CEO of Cancer Australia, delivered an address on the Palliative Care Clinical Trials Collaborative (PaCCSC). Thanks to Professor Janet Hardy for this summary of the progress of PaCCSC to date.

The Palliative Care Clinical Studies Collaborative (PaCCSC) – progress to date

Flinders University's Department of Palliative and Supportive Services has been awarded a contract from the Commonwealth Department of Health and Ageing to lead a national multi-site clinical research collaborative - the Palliative Care Clinical Studies Collaborative (PaCCSC).

There are a number of drugs that have been identified by health professionals in palliative care as priority drugs for practice. Many of these agents are not supported by the Pharmaceutical Benefits Scheme (PBS) however. The primary remit of this research collaborative is to gather the evidence necessary to determine whether these drugs should be put forward for consideration of TGA and PBS approval. This applies not only to the individual drugs, but also the specific indication for which they are being used.

The infrastructure to support the PaCCSC has been established and the various committees that underpin the process have met on several occasions. The Management Advisory Board, the Scientific and the Trial Management Committees are chaired by Professors Felix Bochner, Andrea Mant and Janet Hardy respectively. Committee membership is made up of expert advisors and PaCCSC collaborative members. Five sites around Australia, selected on their extensive research experience, have been contracted to undertake the first round of studies. These sites are:

- Flinders University/Southern Adelaide Palliative Services (SAPS)
- Sydney Cancer Centre
- Sydney South West (western zone) Area Palliative Care Service
- WA Centre for Cancer and Palliative Care (WACCPC)
- Centre for Palliative Care Research and Education (CPCRE)/Mater Health Service
- Peter MacCallum Cancer Institute (Peter Mac)

Trial Sub-Committees have been formed for each of the 6 drugs chosen for the initial studies and considerable