Newsletter

Issue
01
October
2012

This Issue

Welcome to the first issue of the
LOROS Research Newsletter

a regular update, designed to keep you informed about the latest developments in research activity at LOROS.

Interested in research but think you can't do it?

Talk with Christina Faull or email her at: christinafaull@loros.co.uk. We'd like to know if seminars on 'introducing research' or 'beginners research' would be useful to you.

The LOROS Research Committee

The committee is chaired by Dr Christina Faull who is the lead for research at LOROS. The committee makes sure that all research LOROS is involved in is of the highest quality and complies with standards. The UHL Research and Development department supports LOROS in this. If you are thinking of doing a project, the committee need to hear about it as early as possible to help you get it off the ground.

Would you like to join the LOROS Research Committee?

The LOROS Research Committee is looking to extend its membership to staff who hold a full Masters (MA or MSC) qualification and who would like the opportunity to continue to be involved in research.

The group's prime objectives are:

- To enable LOROS to develop its research capacity and increase research output
- To assure the governance of research undertaken with patients, carers, staff or volunteers

It works to achieve this in the following ways:

- By considering research proposals
- Giving authorisation for the development of research projects at LOROS
- Looking at the strategic direction for Research at LOROS
- Looking at ways to develop staff support and capacity for research

The group meet every 3 months.

If you would like to be part of this group, then please email Dr Christina Faull: christinafaull@loros.co.uk

LOROS
Hospice Care for Leicester, Leicestershire & Rutland

The 9th Palliative Care Congress took place at The Sage Gateshead in Newcastle, from March 14th - 16th 2012. The event was attended by Christina Faull; Sarah De Vos; Cassy Rowe-Haynes; Jane Wale and Rachel Atkinson.

Reflections on the Palliative Care Congress 2012...

Dr Cassy Rowe-Haynes...

This is the first such meeting I have been to and it was a fantastic opportunity to hear about new innovations and research in the field of Palliative Medicine; through attendance at the free paper sessions, master class sessions, symposiums and via review of others' research posters. A highlight was certainly the chance to hear respected eminent colleagues in the field of palliative medicine speak. The concept of dignity therapy as presented in the words of Harvey Chochinov was both engaging and memorable

The timetable was varied but for me several messages emerged:

1. The importance of good quality research in palliative medicine to inform future developments in care and for the credibility of the speciality.

2. Dissemination of research findings is likely to change in the future taking account of emerging technology. The use of online resources and sharing systems e.g. blogs, forums and web pages to disseminate research activity and results as opposed to merely publishing in journals is a reality and I need to keep up to speed with these technologies to keep abreast of new developments.

The poster presentations and displays were an excellent way of seeing what other teams and localities were focusing on in terms of their research. The BMJ Supportive and Palliative Care Journal published all abstracts from the event and during the 3 days I starred certain poster abstracts which I felt might be pertinent to review in terms of my clinical practice and in terms of development of services in my area. These included for example several audits looking at steroid prescribing, use of IV medications in refractory symptoms and pictorial prescribing of Fentanyl for breakthrough pain.

I had an abstract accepted for poster presentation entitled 'Exploring issues for doctors surrounding the withdrawal of NIV at the request of patients with MND.' Preparing for this poster presentation and the work behind the findings gave me an insight into important research processes including; undertaking a literature search, development of a questionnaire, interpretation of qualitative data and writing a scientific abstract. Comparing my poster to others at the Palliative Care Congress was a useful learning exercise i.e. seeing what works well and how to catch people's eye when presenting your findings in this manner.

Overall the Congress was an excellent development and learning opportunity with clear relevance to clinical workload. . I certainly left this Congress buzzing with ideas and an energy for more knowledge and I would recommend it to anyone thinking of attending next year.

Reflections on the Palliative Care Congress 2012 (continued)...

Dr Sarah De Vos...

I found the free papers particularly useful, as these were frequently presented by clinical colleagues doing research as part of master's and doctorate studies. Their sessions gave me insight into common challenges and hurdles encountered while doing clinical research, and helped me appreciate that research can be done by people such as myself who have never done any before.

One session I gained a lot from was the Palliative Care Research Society Masterclass 'Getting Research into Practice – Practical Steps'. Professors Jack and Downing acknowledged that while getting research into practice is often intended, it generally takes second place to seeking journal publications and conference presentations.

They encouraged the importance of identifying a key goal or goals; considering the audience(s) most affected by the research and hence considering the most effective way to reach each audience (e.g. blog, journal publication, YouTube video, podcast, Help the Hospices newsletter); and planning the timing of the dissemination of information (considering when each aspect should occur; a phased approach; clear roles and responsibilities for dissemination activities).

They showed the YouTube video of Vinnie Jones performing hands-only CPR, to demonstrate a recent example of getting the evidence from research ('the key message') into the public arena. They also gave the example of using the radio as a means of disseminating information in Uganda, as the majority of people there listen to the radio.

This session will influence my practice in encouraging me to think creatively about how to disseminate information, not just following any research I do, but also when teaching students or colleagues about palliative care. I will also start thinking of this at the beginning of any research project rather than at the end, once I have my results.

Rachel Atkinson...

There were many different speakers categorised under different headings. I chose to attend sessions and view posters that were pertinent to my practice:

- Breathlessness
- Rehab research
- Non cancer palliative care patients
- Place of death

One of the papers that I found interesting was on Goal Setting in Palliative Care. It was presented by Sally Boa, an OT working at Strathcarron Hospice. As an Occupational therapist providing rehabilitation, goal setting is pertinent to my practice but can be difficult due to a patients disease trajectory. Sally had completed a literature review with the view of identifying a conceptual framework to underpin goal setting. Sally identified 16 papers which all varied in their quality and focus. It was found that there is no clear definition of goal setting in palliative care which for me supports anecdotal evidence that it is difficult and that as an MDT we all work differently in defining and setting goals. Sally's presentation reinforced that goal setting is an important component of palliative care but is slightly different in palliative care as opposed to general rehabilitation.

A further session that I attended was on Rehabilitation research by Dr Gail Eva. It highlighted that there are gaps in rehabilitation research but also acknowledged that it can be difficult when working and also trying to undertake research. Gail was keen to encourage therapists to undertake research to help inform policy and practice and to set up a research network.

I would like to thank the research committee for awarding me the grant and providing me with the opportunity to attend the conference.

Reflections on the Palliative Care Congress 2012 (continued)...

Dr Jane Wale...

Several posters and presentations focused on the palliative management of non malignant disease and the key findings which will influence my practice are listed below:

- Heart failure

Hookey et al undertook an audit of physicians understanding of palliative care needs of heart failure patients. They found that only 6% of patients discharged were thought to be palliative, but actually 40% died within 6 months, emphasising the need to engage with general physicians and address their training needs.

The same group set up a community based subcutaneous diuretic service for end stage heart failure patients and found it was valued by patients and saved money. They also presented their experience of using tolvaptan, a vasopressin antagonist and found it to be safe, well tolerated and effective for reducing congestion in end stage heart failure patients.

- Renal failure

Hussain et al conducted a study of 441 patients with chronic kidney disease stage 5 who chose to have renal replacement therapies or conservative management. They found that for patients over 80 years old, with high comorbidity scores and low performance status, renal replacement therapy did not offer a survival advantage.

- Respiratory failure

Scaife et al aimed to assess the quality and effectiveness of end of life care for patients dying in hospital from COPD. They found that a ceiling of care was only documented in 53%, EOL drugs were only prescribed for 28% and only 32% were on the LCP. They concluded that there is inadequate planning for end of life for patients with COPD.

- Parkinson's disease

Samuel et al presented a study looking at the prevalence and management of symptoms in patients with Parkinson's disease at the end of life. They found that hallucinations, cognitive difficulties and swallowing difficulties were common and that recognition of the dying phase was difficult. They recommend continuing dopaminergic therapy as long as possible and suggest that rotigotine patches have a role to play.

New Research Support Administrator: *Welcome Idi!*

Idi has had several administration posts at LOROS and in September she started in a new post which is underpinning the development of research at LOROS. Idi will be helping with all research projects that happen at LOROS. She also keeps the research notice boards interesting and over the coming months will be making research more of a focus at LOROS. Watch this space!

CPEP: Centre for Promotion of Excellence in Palliative Care

Research activity is flourishing at CPEP. Gill Plumeridge has started this month and will be studying for a PhD exploring the end of life care needs of families of with inherited genetic disorders. Gill will be coming to LOROS soon to get to know our work.

Dr Richard Kitchen is a registrar in palliative medicine in the West Midlands who is now working at CPEP developing and assessing an educational intervention with surgeons and anaesthetists to help them make best possible discussion for people who have advanced illness.

LOROS Success...

Christina Faull and Cassy Rowe-Haynes have been successful in being awarded a grant by the Motor Neurone Disease Association to continue work, initially funded by LOROS, to explore the experiences of people involved with patients who ask that the ventilation be stopped. LOROS is working with Kay Phelps and Emma Regen at the University of Leicester and also with Dr Oliver (Wisdom Hospice, Kent) and Dr McDermott (MNDA care centre University of Sheffield).