

Research NEWS January 2014

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Recognising the Value of Hospice Research

By Heather Richardson, National Clinical Lead for Help the Hospices

The research team would like to thank Heather Richardson, National Clinical Lead for Help the Hospices, London, for her support of the progress LOROS Hospice is making in the area of research. Below, Heather offers a few words as to why research is vital to the future of hospices, and how other hospices can become involved in this important area...



The Commission into the future of hospice care has highlighted in its final report how important it is that hospices engage in the activity of research. It suggests that this is a vital development on the part of hospices for a number of reasons – to ensure that hospices provide care that has been evaluated in terms of effectiveness and cost effectiveness, and to contribute to the much

needed evidence base for hospice care.

Whilst those working

in hospices are confident that their care really makes a difference to those that they support, there is often relatively little data to support that belief. Commissioners, Government and others are increasingly demanding of evidence of the value of hospice care as a basis for investment into this service for people who are dying or bereaved.

Commission members received a valuable report from the team at the University of Lancaster with some recommendations about how hospices become more research active. It identifies a variety of options for hospices, ranging from reading and implementing relevant research findings to developing proposals for new research to be led by the hospice, in partnership with academics.

LOROS Hospice is to be commended in its commitment to undertaking and promoting research as part of its everyday work. Its appointment of a research champion within the hospice, its relationships with academic centres and its efforts to engage its staff in research via a regular magazine are vital steps in making the hospice research active. Help the Hospices is keen to learn from LOROS and to help other hospices take similar steps.

A copy of the report mentioned in Heather's article can be downloaded from: www.helpthehospices.org.uk/commission

In addition, Help the Hospices have produced a report looking at: *Research in Palliative Care: Can Hospices Afford not to be Involved?*

<http://www.helpthehospices.org.uk/our-services/publications/publications-catalogue/?entryid219=138295>



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Hospice Care for Leicester, Leicestershire & Rutland

Being there for you
and your family

Happy New Year... from the LOROS Research Team

We would like to begin by wishing all our readers a Happy New Year!

You will see that activity has continued to grow since our last newsletter in September...much of this edition has a very Italian feel, following Christina's recent attendance at the Allied Professionals Forum in Milan and the addition of Marco to the team.

It is also important to recognise the support given by Heather Richardson in her article, and hope that we can continue to make strides towards developing research at LOROS.

Thank you to all LOROS staff and volunteers who completed the recent

research questionnaire - we hope to share some of the findings from this with you in the next edition.

We also hope that those findings will help to shape the ways in which we continue to achieve our research goal in the years ahead, for: *a focussed programme of research that builds on the unique contributions of LOROS services and skills of its staff and contributes to the care of patients and their families and the development of practitioners.*

We look set to have a busy year ahead of us, with proposals being submitted, 15 poster presentations going to the National Palliative Care Congress,



Members of the LOROS research team:
(left) Prof. Christina Faull;
(center) Idaliza Garner; (right) Dr Zoebia Islam

Harrogate, in March and other new and exciting developments taking shape.

We hope you enjoy reading our latest news, and look forward to sharing future developments throughout 2014.

The 2013 Help the Hospices Conference By Fiona Brant, Advancing Practice Development Facilitator

Several LOROS staff attended this year's Help the Hospices conference in Bournemouth, the theme this year was 'Fit for the Future'. This was a chance for member hospices to meet to network and participate in discussions around the challenging times that hospices face today.

There were four key themes of the conference - Strategic leadership, Organisational culture & workforce, Innovations in care and Building the Evidence Base. These themes provided the structure for five parallel sessions that ran throughout the conference, these sessions included: Hospice as research-active organisations, working differently in hospitals & the presentation of various conference papers. Staff attended different parallel sessions to ensure all key messages were gathered for further discussion and debate.

Furthermore, a plenary session was held reviewing the recommendations from the Commission into the Future of

Hospice Care and a printed copy of the final report was made available to all delegates.

The plenaries also provided the opportunity for the delegates to hear a variety of inspirational speakers, including Professor Alex Jadad from The Centre for Global e-health Innovation, delivering a Plenary on 'Dying healthy & happy: the most important challenge of our time'. Professor Jadad's mission is to enable people to live full, healthy & happy lives until their last breath, with the aid of information and communication technologies.

LOROS submitted four posters for the exhibition, that were displayed for the duration of the conference. Posters presented were 'VALE: Volunteers at Life's end, the LOROS care homes project', 'ENTER - Enabling nurses to engage in research: developing a culture of enquiry in clinical environments', 'Providing a seamless service - assistant practitioners working across hospice and community settings' and 'But what

happens in a hospice? Interprofessional learning in the workplace'. Very positive feedback was received from the delegates about the research and work carried out at LOROS.

Sheila Markham (LOROS Broadening Horizon Project Lead) delivered a session on the team's work at LOROS, which included a film of the work she has done in promoting Black Minority Ethnic groups utilising our services.

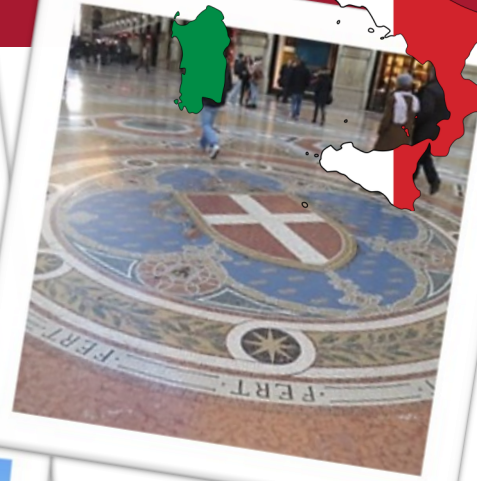
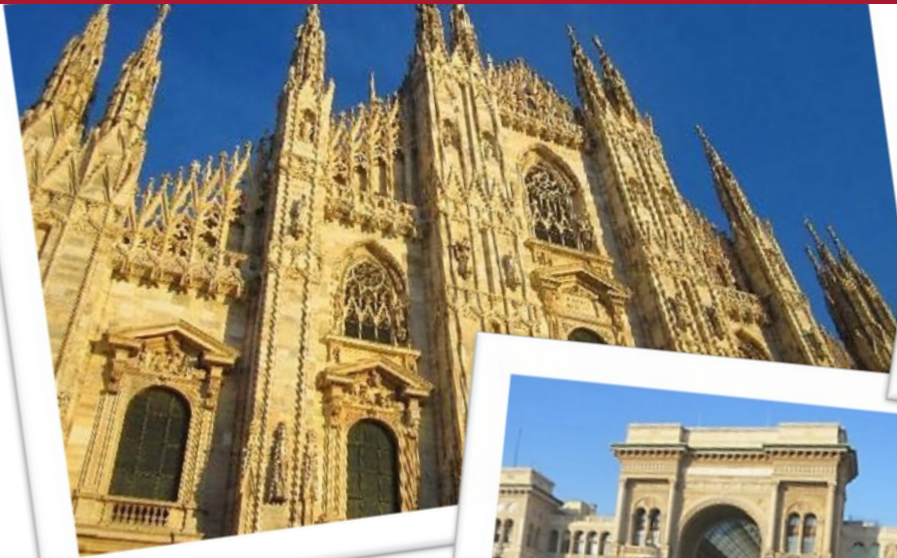
The conference was a busy, full and informative three days, which gave the opportunity to present the work LOROS has been involved with over recent months. It also gave lots of opportunity to network with key colleagues from other hospices to further nurture collaborative working in the future.



Feedback from the December 2013

Allied Professionals Forum, Held in Milan

...Professor Christina Faull



Every year there is an international conference about motor neurone disease which is organized by the British Motor Neurone Disease Association (MNDA) in collaboration with other national charities. The research conference brings together scientists and clinicians and is preceded by a one day meeting for allied health professionals. I was first on the list of presenters at 8.40AM and it was pretty tough for the audience to be focusing so early in the day, many in their second language, on *Withdrawal of*

ventilation at the patient's request in MND: exploration of the issues related to communication. It was really great to be talking to an audience from America, Australia, Scandinavia, Japan and Europe about unique work from Leicester, inspired by the challenges of our work with patients.

talk focused on the considerable communication challenges in this area of care and how for most patient's the time when they can no longer communicate is a tipping point in quality of life and decisions to stop treatments that may prolong life.



Christina Faull (left) in Milan with Sally Light
Chief Executive of the
Motor Neurone Disease Association

Patients with MND are the same the world over but how they are cared for has considerable international variation most especially when respiratory muscles fail. In the UK very few patients receive ventilation through a tracheostomy and this is a much higher proportion in most other countries. In some countries, notably Japan, there is huge controversy as to whether a patient may be allowed to stop their ventilation. The patient's 'voice' is often not heard in research and my

Milan offered a diverse mix: graffiti and ancient marble. The public transport was marvelous but the customer service laughable especially in the hotel restaurant! The conference was interesting but the separation of the allied health professionals meant that other than palliative care no doctors are part of the learning and debates.

Case Stories: A Project Looking at Social Pain & Transnational Dying

By Dr Yasmin Gunaratnam

'Case Stories' is the name of British Academy Fellowship project on experiences of social pain and transnational dying in the UK. When I started reviewing the literature I found that social pain was the least well defined and understood aspects of the palliative care concept of total pain. At a very basic level the [Case Stories](#) project is using stories and art to try and encourage more discussion and thinking about the ways in which social pain can manifest at the end of a life.

As a part of the project I have been building a digital archive of stories and related resources such as podcast interviews with researchers and practitioners, including Professor Christina Faull, on different aspects of social pain. I am hoping that the Case Stories website will be used in palliative care education and training and by dying and bereaved people. One of the highlights of the project was a workshop on social pain that I did at LOROS in July 2013, where I also piloted some of the case stories that I have

been developing, which are fictionalised accounts based upon qualitative interviews with dying migrants and care professionals.

Although my focus has been on migrants, social pain can be experienced by many people, such as those living in poverty or with stigmatisation. So the project has wider implications and I would like to develop it in the future to address other areas of social life.



Dr Gunaratnam is based at Goldsmiths, University of London.

Her book, 'Death & The Migrant', is available to order from:

www.bloomsbury.com

(Quote order code GLR9JP to receive a 30% discount)



A Big Welcome to Marco Pino Who is joining us from Italy...

Marco was recruited as a researcher for the *VERDIS project, back in September. Although employed by the University of Nottingham, Marco will be a regular face at LOROS during the course of the study, and will be based in the Education office. Here is a brief bio about Marco...and we're sure you will join us in welcoming him to the hospice.

After working for several years as an educator in Therapeutic Communities for people with drug addiction problems, Marco decided to do research in the field healthcare communication. He received his PhD in Education at the University of Verona with a dissertation on face-to-face communication in Therapeutic Communities for people with mental health and drug addiction problems.

In his research he has been particularly interested in how the

method of Conversation Analysis, along with other qualitative methods, can be used both to increase our understanding of and to contribute to the improvement of communication practices in healthcare settings.

He is enthusiastic at the idea of joining the Sue Ryder Centre at the University of Nottingham and working on the VERDIS project at LOROS, which he considers to be a great opportunity for him to grow

both as a human interaction researcher and as a researcher in healthcare communication.

If you would like to know more about the VERDIS study, or to ask about participation,

please contact:

Ruth Parry at the

University of Nottingham

ruth.parry@nottingham.ac.uk

(tel 0115 823 0873).

**The VERDIS study looks at video-based communication research and training in supporting shared decision-making in supportive and Palliative Care. It aims to capture practices through video-based research involving experienced clinicians and service-users, and use these in the development and delivery of staff training.*

A Short Film from LOROS Volunteers

By Sheila Markham & Anjana Vaja – Broadening Horizons Project Coordinators



The Broadening Horizons project has aimed to raise awareness in the Minority Ethnic Communities in Leicester, Leicestershire and Rutland about the services, care and choices available for patients with incurable disease approaching the end of life.

The project, led by Sheila Markham and Anjana Vaja, enlisted the support of trained volunteers from diverse

backgrounds, who spoke the main South Asian languages of the locality, plus several others, which helped them greatly when engaging with members of the public.

With the support of Meera Darji, an undergraduate film maker from Coventry University, the volunteers assisted in the making of a short film.

Meera was keen to make short films focusing on topics that can, at times, feel uncomfortable. Her previous work includes examining the effects of redundancy, and the poverty in early life as a grandparent.

The undergraduate film maker was introduced to the Project by her mother, who, at the time, worked in administration at the Hospice.

The script was deliberately simple as none of the volunteers had acting

experience. They were sent their lines a week before filming, which took place over two weekend mornings. The clip is true *Cinéma Vérité* – rehearsals took place for a couple of minutes and then the film was shot. The multiple language skills were utilised; English, both spoken and as sub-titles, runs throughout, with different scenes delivered in Gujarati, Hindi, Urdu, Punjabi or Marathi.

The goal of this short, amateur collaboration was to showcase the diversity and versatility of the project volunteers, who give basic information regarding the Hospice and its services using languages which are familiar to many members of the population of the area. The hope is that when it is used in awareness-raising sessions it will encourage more patients from the many diverse minority communities to consider using the palliative care services available to them.



The Broadening Horizons
Volunteers Group

If you would like to view the clip, it can be found at the following link: <https://vimeo.com/68435490>

Sheila Markham will be presenting a 1 hour lunchtime session about the project on February 10th, from 12:00 - 1:00pm. For more information see *Dates for the Diary*.

Research Colleagues from Leicester University

Two faces you may have seen in the hospice over the past 5 years or more, are those of Kay Phelps and Emma Regen, researchers with the University of Leicester. They are currently working on a study led by Prof. Christina Faull, exploring the withdrawal of ventilation at the request of a patient with motor neurone disease, from the point of view of doctors, health care professionals and relatives.

For the past twenty years Kay has undertaken research in the area of health and social care services. In recent years Kay's work has focussed on end of life care, evaluating service provision

locally for older people and minority ethnic groups. Kay's expertise lies mainly in the design, conduct and analysis of qualitative studies but includes; national survey; systematic review; service evaluation; database design; and secondary data analysis.

Emma has been a Research Fellow since 2004. With a background in medical sociology, Emma is experienced in using a range of qualitative methods in both academic and applied research contexts. Her research interests include the provision of health and social care for older people and end of life care.

Both Kay and Emma have worked collaboratively with LOROS on previous occasions, including an evaluation of a Leicestershire based service aimed at

extending choice for older people at the end of life (Decisions at Life's End - DALE) and an examination of place of death and end of life care for people from minority ethnic groups in Leicestershire.



Kay Phelps (left);
Emma Regen (right)

A Step into Research: The Experiences of Two Students Undertaking the Foundation Degree EBP Module



Carolyn Suffolk (left) and Elaine Whitmore

Tell us a little bit about your yourselves...

Carolyn: I have worked as an HCA for fourteen years; five on the ward and nine within Lymphoedema. Our roles are very varied and interesting; mainly assisting the Community Nurse Specialists, to ensure the smooth running of the clinics.

Elaine: I have worked at LOROS for thirteen years. My role is as an HCA in Day Therapy, assisting with patient care and in Lymphoedema, assisting the CNS nurses in the clinics.

What attracted you to the Evidence Based Practice research-module of the Foundation degree?

Carolyn: It has been very difficult for us to find a course relevant to our work in outpatients. We have been involved in research in the past, but we have never really understood the reasoning behind it.

Elaine: The recent research questionnaire that went out to staff, got me thinking about research and as we have been involved in research before, I was interested to find out more about why research is important and why we do research.

How do you feel about the prospect of studying?

Carolyn: It's quite daunting and challenging, but I am really looking forward to it.

Elaine: I find studying quite challenging, but I feel by doing some studying it will help me in my practice as a HCA.

What are you hoping to take away from the course?

Carolyn: I am hoping to gain a more in-depth knowledge about EBP and why it is important.

Elaine: We're hoping to be involved in research this year, within the Lymphoedema

Carolyn Suffolk and Elaine Whitmore are HCA's based in Lymphoedema Outpatients, at LOROS. Both are enrolled on the Evidence Based Practice module of the Foundation degree, which will help them to develop some of the key skills used within research; such as how to investigate research topics, conduct analysis, and evaluate and interpret research findings.

We asked them to share their thoughts about the module and what they hope to gain from their learning, and we will be checking back with them in the next edition, to find out how they are getting on...



team, and I'm keen to gain more knowledge on why we do research.

The EBP module will equip you with some of the skills required for research; how do you think that you will be able to use these skills to become involved in research in the future?

Carolyn: We are hopefully going to be involved in research in the coming year, so the skills we learn will enable us to understand why and how the study is being carried out, and what the results will show.

Elaine: In the last research study we did, we helped to collect data and found being involved in the research interesting.

Why do you think research is important to patient care and to the development of services?

Carolyn: It offers an opportunity for better patient care and greater knowledge for staff.

Elaine: It's important for patient care that we improve our knowledge. It's also good for us, as individuals, to keep up-to-date with mandatory training and education.

What would be your advice to other people who are thinking about studying, but who haven't yet 'taken the plunge'?

Carolyn: I would say to anyone *Have a go!* Everyone involved in the course is so helpful.. You may enjoy it!

Elaine: Run!!!! ...but seriously, find the subject you're interested in, go and see the education team, and take the plunge!

If you would like more information about the EBP module, or have any questions about the Foundation degree, please contact Philippa Graham, Education Facilitator: Email: philippagraham@loros.co.uk Or phone: 0116 231 8455

Join us for the first in a series of NEW research events:
A Cup O' Learning & A Slice O' Cake:
PC1, LOROS Hospice, 12:00 - 1:00pm, 10th February 2014
 The first of these will be presented by Sheila Markham, and offer more information about the achievements of the 2011-2013 Broadening Horizons project. These sessions are free to attend, and open to all staff (cake will be provided!) To reserve a place, please email: PaigeMurney@loros.co.uk

Good Clinical Practice Training Session (open to all LOROS staff)
Frizelle 1, LOROS Hospice, 9:30 - 11:30am, 28th February 2014
 GCP is an international ethical and scientific standard for the design, conduct and record of research involving humans. This session is open to all staff with an interest in research, and will provide you with a certificate for GCP, valid for 2 years. To reserve a place, please email: idalizagarner@loros.co.uk

10th Palliative Care Congress
The Harrogate International Centre, 12th - 14th March 2014
 For more information, visit: <http://www.pccongress.org.uk/>

Marie Curie Annual Palliative Care Research Conference 2014
Venue: The Royal Society of Medicine, London, 28th March 2014
 For more information, visit: <http://www.mariecurie.org.uk/>

Leicestershire, Northamptonshire & Rutland (LNR) Audit & Research Day
Frizelle 1, LOROS Hospice, 10th July 2014
 This event is for palliative care doctors/is open to other professionals within Leicestershire, Northamptonshire & Rutland. The programme includes presentations of local research and clinical audit projects. For more information, please contact Professor Christina Faull: christinafaull@loros.co.uk



If you have an item of research news that you would like to share in the next edition, or would like to comment on any articles in this issue, please contact: idalizagarner@loros.co.uk