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Annual LOROS Lecture March 2019 Life's hard and then you die: exploring end of life concerns within the homeless population

We were excited to live stream Wendy Ann Webb's lecture about the end of life concerns of homeless people.

You can still view the lecture at <https://twitter.com/LOROSHospice/status/1111328220744433665>

If I see someone like ... dying on the floor and all that, I mean, I think to myself ... 'that could be me you know?' [...] and you're thinking 'well ... one day that's gonna be you' ... I know it worries me completely

PhD research participant no. 1



Key messages:

What can hospices do?

- Nominate homeless 'Champions' within the hospice
- Appoint community engagement staff
- Build links with local hostels and homeless services
- Develop capacity to in-reach to hostels through CNS and hospice at home teams
- Deliver palliative care study days for hostel staff
- Fund-raise for an End of Life/hospice bedroom established within a hostel
- Consider project ECHO for hostels
- Encourage people with lived experience of homelessness to serve in volunteer roles



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LOROS

Hospice Care for Leicester, Leicestershire & Rutland

LOROS at the 2018 Hospice UK conference, Telford

In November staff from across the hospice services had the opportunity to attend and present some work at the national hospice conference. The work we showcased was very diverse and the 12 posters can be viewed at <https://www.loros.co.uk/education-training-research/research/research-posters/>

Three staff received a research bursary to support their attendance. They feedback on the impact of this on their practice here.

Suzann Chantrill & Volunteer Ward Companions

I am the Clinical Volunteer Co-ordinator at LOROS. I have never been to a conference before and I was really looking forward to gaining knowledge to provide professional development opportunities for the Clinical Volunteers and myself and looking at the future planning with new ideas from other Hospices.

There was one talk that really caught my attention: Living Well with Dementia. The talk was interesting as a larger proportion of patients now not only have Cancer but also other illness too. To be able to hear and see what Dementia is like to live with has provided me with a better understanding of caring for people with Dementia. I also gained inspiration from discussions about Dementia Cafes, Bereavement Groups and also utilising young people in our service.

Reflecting on these experiences, I am very keen to look at a men's group that focuses on gardening, photography, talks about sailing, football etc. An additional idea to provide an inclusive environment across the Hospice would be a cinema afternoon with an array of choice and popcorn of course!

Further extending my interest from the dementia talks, a colleague has found a free on-line course that is available to volunteers to give better understanding and care for the ward companions and day therapy Volunteers.

My poster display resulted in meaningful conversations during the conference, follow-up emails and phone calls regarding the Ward Companions. Two visits were arranged from other hospices to visit the ward and to explore the role of the Ward Companions.

The Hospice UK Conference was really interesting and it has enabled me to move the clinical area forward for the future. The things I have learnt are that you have to step out of your comfort zone to embrace change and forward thinking for the future of Clinical

Volunteers to bring normality and a bit of fun on the way.



Elaine Godber: A passion for Virtual Reality

I am extremely honoured to have received a Wolfson bursary to attend the Hospice UK Conference and to showcase the LOROS Hospice virtual reality (VR) project *I Experience VR*. The theme of the conference was *Transforming Patient Care*, and VR is an exciting prospect in this. It offers an escape, a distraction, stimulates conversations and our evaluation shows that patients are reporting being more relaxed and in less pain.

Our *I Experience VR app* is transforming patient care. Cicely Saunders said "You matter because you are you and you matter to the end of your life, we will help you to not only die peacefully but to live until you die". *I Experience VR* can help a patient "live" for a while, watching the waves coming to shore or be at the park feeding the ducks so transforming their current environment and enhancing their wellbeing.



The conference offered me a platform to showcase the LOROS Hospice virtual reality journey including an evaluation of the impact on mood and pain and the functionality of the VR headset. It was also an opportunity to raise awareness of our partnership consortium which provides easy, off-the-shelf access to our unique Hospice VR app *I Experience VR*. In the space of two years our library of films has grown to over 50 engaging and therapeutic films from all over the world.

Through the many delegates I engaged with whilst showcasing VR, I recognised that each Hospice does have a different face and is as individual as the community it serves and that whilst it is important to recognise individuality it is only by joining individuals together and becoming one team focusing on one goal that relevant change will happen.

The talk that was most relevant to me was *Virtual reality distraction therapy in palliative care: a feasibility study* presented by Mark Mills from Liverpool Hospice. Mark spoke about previous studies using virtual reality in hospital settings which



were beneficial in certain situations (such as distraction therapy for pain management) but that there was little data in the literature concerning the potential benefits of VR therapy in palliative care (Bower, 2014). Mark spoke about conducting a feasibility study according to the Plan, Do, Study and Act (PDSA) quality improvement cycle.

Following this talk, I was compelled to share with the audience that LOROS Hospice had already evaluated patient responses to virtual reality as a distraction therapy and invited everyone to visit our stand to experience VR for themselves and to view my poster! (see my poster on the next page).

As hospice care changes, maybe, VR could be one tool that unites all Hospices so that more patients have the opportunity to benefit. LOROS Hospice is truly at the forefront of this.

I EXPERIENCE VR (VIRTUAL REALITY)

DEVELOPMENT OF LOROS HOSPICE VR THERAPEUTIC DISTRACTION THERAPY APP



Background

One year on from commissioning the first virtual reality (VR) film of a local park aimed at bringing relaxation and distraction therapy to patients whose lives have become restricted due to their illness the chance to see the world from the comfort of their chair or bed, we have developed the project into a growing library of therapeutic films stored safely within its "I Experience VR" App.

A robust evaluation study of patient response is underway to establish the impact on transforming patient care.

To reach out to more patients it has engaged with other Hospices and care homes with an invitation to join a partnership consortium and is constantly re-evaluating its offering.

Aim

- Create a library of films designed specifically for people with restricted mobility in mind. By using the VR headset a patient actually feels like they are there.
- To provide patients with relaxation and calmness and provide conversations of meaning to the patients and their families
- To be simple to use for all health care professionals offering a different way to engage with patients and their families
- To invite other Hospices, care homes and organisations to join I Experience VR partnership consortium.

Methods

A project methodology approach has been used to plan "I Experience VR":

- A Terms of Reference and Project Plan produced to guide direction
- Staff training and VR Champion recruitment programme instigated
- Evaluation of patient experiences using a mixed methodology approach
- Commissioning further VR films
- Expansion of partnership consortium
- Creative marketing - I Experience VR brochure produced

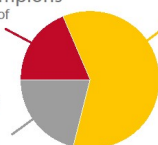


Results

Training

30 LOROS VR Champions trained across all sectors of Hospice Care

32 VR Champions trained at four Partner Hospices



82 LOROS Ward Nurses and HCA's attended I Experience VR awareness sessions

Interim Evaluation July 2018

57 patients completed a questionnaire before and after using VR

Do patients like using VR?

- 51 yes a lot
- One disliked a lot
- One neither liked or disliked
- Four did not answer the question

Patient outcomes

- 54 said the experience was more than just enjoyable or fun.
- 38 had no bad experiences or problem. Most problems were with the equipment not the VR experience
- Almost all patients reported feeling more relaxed and calm after immersing themselves in the films
- 31 patients were experiencing pain of whom 22 had a score of >5/10.
- 16/22 reported improvement whilst using VR
- Six said they were less aware of their pain
- 10 said they had no pain at all

Results

Films

- Eight films in I Experience VR APP
- Four commissioned films, one being a Hospice Tour aimed at reducing anxiety before visiting a Hospice
- Four gifted films



We're hosting the world's first VR for Good filmmaking competition

- to grow our library of therapeutic films and extending the experiences on offer

Results

Partnership Consortium

- Four Hospices have joined our partnership consortium
- Engaged with five more Hospices
- Engaged with one care home
- Engaged with three corporate organisations for their wellbeing programme



Coming soon

- A mindfulness talk to accompany our beach film
- A Gift of Mindfulness as a takeaway box to prolong the relaxing experience at home or in their Hospice bed

The Future, technology does not stand still

- We have upgraded our Samsung phone attached to a VR headset to the recently launched Oculus Go, a cheaper and lighter VR headset offering similar great quality
- The future is beyond our imagination but for now we are privileged to be able to offer I Experience VR films to our patients and families and all that it brings to them.

"You get so immersed in the experience you can almost feel the sun on your back and the soft sand squashing between your toes."

Mick Jones, LOROS Hospice patient

"Her last wish was to go to the seaside again."

Helene Morgan, LOROS Hospice Nurse

Ready to join our I Experience VR partnership consortium?

We invite each Hospice, care home and business organisation to take the opportunity to join us on our journey and share these experiences with your patients, families and staff.

Elaine Godber, I Experience VR Lead
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LOROS

Hospice Care for Leicester, Leicestershire & Rutland

Being there for you
and your family

LOROS at the 2018 Hospice UK conference Telford

Helen Robson-Swift Therapy Assistant

I have picked out a few sessions to share which had a particular value for me.

- Reflections on families and caring in the 21st century

This session provided a brief global update on carers research together with what's new in the UK. It featured headlines from the recent national survey exploring carers support in UK hospices, where are the gaps and how can we become more systematic and relevant in our support for family carers. It also featured a case-based focus on the common psychological defences that families use to cope with uncertain and gloomy prognoses, along with practical ideas and tools for front-line palliative staff to honour the psychological aspects of care which often dominate the experience of illness.

- A re-design of day therapy services: from social groups to 'specialist care' and back again

Emily Stowe, Day Therapy Manager, St Clare Hospice chaired this session of four abstracts which are in a conference supplement published by BMJ Supportive & Palliative Care, an official journal of Hospice UK.

- 'Bounce Back Boy' tackling the challenges of transition, discrimination and indifference – using personal experience as a catalyst for change and improving care

An extract from 'Bounce Back Boy' was shown, a film which portrays the life and death of Josh Cawley, and to preview new educational resources which accompany it. Aimed at health and care staff working across all care settings, the resources raise awareness of the multiple challenges that can arise when a young person with complex needs is dying and highlight the importance of tailoring care to individual and family needs. The play explores the story of Josh, and of Lynn Cawley who adopted him, and the situation in which his needs were perceived too 'complex' for a hospice. After the film Lynn was joined in a discussion of her experiences by colleagues from Hospice UK, the Royal College of Nursing, and Skills for Care who have developed the resources which bring together lived experience with personal narrative and reflective practice.



The real Josh Cawley

In other news.....

We are delighted to announce that Christina Faull has been appointed as honorary professor and Zobia Islam has been appointed as honorary research fellow at the University of Leicester



This resource to support training of health and social care workers in conversations with people about dying was launched at the national palliative care congress. The evidence based resource is a collaboration between LOROS and Professor Ruth Parry and her team at Loughborough University. You can find out more at <https://www.adozeneggs.co.uk/portfolio/project/real-talk/>

Work, Life and Volunteering



Dr Katharine Venter,
Associate Professor in
Sociology, University of
Leicester Business School

Dr Katharine Venter is the lead for this study funded by the British Academy at the University of Leicester Business School aiming to contextualise the experiences of volunteering by exploring interconnections between voluntary work, paid work and home, family and leisure lives. LOROS has been one of 6 case studies of non-profit organisations in health and social care. The research used an ethnographic approach of observations, conversations, volunteering diaries, one to one and focus group interviews. Katharine presented the findings at LOROS in March and we learnt about the themes of 'messy volunteering' (responding to what's required on the day e.g.) 'tidy volunteering' (tasks defined e.g. lottery collection) 'tea and cake volunteering' (e.g. our snack bar) and 'real volunteering' (e.g. supporting with patients in day therapy).

An important finding is that what makes for good volunteering is to feel valued and valuable.

Many thanks to all the volunteers at LOROS and especially to those that have taken the time to be part of this study.



Meet Matilda Hanjari

Matilda joined the LOROS team in October 2018 as a research associate on the Thinking Ahead project. Previously, she worked at the Centre for Health and Development (CHAD) at Staffordshire University - a unique collaboration between local public services and universities in Staffordshire and Stoke-on-Trent for tackling health and social inequalities. At CHAD Matilda was involved in several health research projects including a study on health professionals' views and experiences of providing End of Life Care. Prior to that she worked at University of Central Lancashire as a Research Assistant on various research projects including an evaluation research project on "Aiding Detection of Atrial Fibrillation in Primary Care using Mydiagnostick".



Matilda has amassed a range of research experience and skills to bring to her role at LOROS. Matilda is particularly interested in the NIHR funded Thinking Ahead about Medical Treatments in Advanced Illness: A qualitative study of barriers and enablers in end-of-life care planning with patients and families from Black, Asian and Minority Ethnic backgrounds as it address issues around diversity and disadvantage. This is an interest which originates from her previous roles where she worked with various groups from marginalised communities.

Meet our Research Nurse Natalie Rich

I started at LOROS in October 2018 as a Research Nurse. One of my main responsibilities is to identify, screen, consent and recruit participants to the national NIHR portfolio research studies being undertaken at LOROS. I am based in the LPDC but you will see around the hospice and outpatients.

I have over 8 years Research Nurse experience working at University Hospitals of Leicester. I worked on the 100,000 Genomes Project within Genetics working with patients with suspected or already diagnosed cancers and patients along with their families with rare diseases (adults and children). It was my role to screen volunteers for their eligibility for the project, take the families through the consent process and collect the DNA samples by taking a blood test for their whole genome sequencing. Prior to this I was one of the Critical Care Research Nurses. During this time I co-ordinated a variety of national and local studies which involved monitoring patients and recording observations, administering study drugs, taking blood samples, processing blood samples in the labs, conducting questionnaires and interviews in the intensive care and anaesthetics setting.

I find Research very rewarding and want to improve care for patients in the future. Having worked in genetics and Critical care I have experienced and learnt from many different situations which I feel will help me in my role at LOROS. I live locally with my fiancée and our 6 year old daughter who keeps me very busy out of work! We are getting married this July and I'm approaching a big birthday so there will be lots of celebrating for me this summer.



Breaking News

The European Journal of Palliative Care have allowed free access to their journal archive. Further information can be found here: <https://eapcnet.wordpress.com/2019/07/03/european-journal-of-palliative-medicine-free-access-to-the-complete-archive-for-all/>



East Midlands
Research and
Audit

1st October
2019
1.30pm to 5.00pm
Lunch at 1.00pm

Free to all
Book at
research@loros.co.uk

LOROS
Professional
Development
Centre

Annual lecture

March 24th 2020
5.30 pm for 6-7pm
lecture

Details to follow soon

LOROS Professional
Development Centre