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The *European Journal of Palliative Care* is an official journal of the European Association for Palliative Care, Onlus (EAPC). The EAPC was established to promote palliative care in Europe and to act as a focus for all those who work, or have an interest, in the field of palliative care.

It is the goal of the EAPC to gather and represent all healthcare professionals and volunteers working in palliative care across Europe and to include as many members as possible in the daily life of the association.

The EAPC was created in 1988 by 42 founding members from nine European countries. It has grown rapidly since its foundation. In 2017, the EAPC has individual members from 48 countries across the world and collective members from 56 national associations in 32 European countries, representing a movement of many thousands of health- and social care workers and volunteers contributing to palliative care.

If you would like to know more and/or become a member of the EAPC, please visit **www.eapcnet.eu**

Note from the publisher

It is with regret that after 24 years The *European Journal of Palliative Care* (*EJPC*) is closing its presses. On behalf of its publisher, Hayward Medical Communications, the *EJPC* would like to thank the current Editors, Drs Ros Taylor and Sarah Russell and Editorial Board members, and all previous Editors and Editorial Board members for their efforts over the last 24 years. We could not have done this without you.

The *EJPC* has been a wonderful journal to work on and and it is with heavy hearts that we have made this decision. We feel honored and privileged to have contributed in whatever small measure to the field of palliative care.

Submissions

The *EJPC* is no longer able to accept submissions for articles. Articles already submitted but not yet published are currently in transit for an alternative outlet. For all editorial enquiries, please contact ejpc@hayward.co.uk

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What next for knowledge ..?

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Sam Guglani wrote about the place of death in medicine last week. He reminded us that 'Medicine, like religion or art, is one attempt to fathom death and therefore to fathom life, suffering and loss'.[1] This has been a little easier the last 24 years with the knowledge and practice shared by this journal. Shared with countries where dying in pain is the norm, where there are no opioids to soothe, but also with countries where every organ can be transplanted, where people have choices. The extremes of medicine can be democratised by knowledge, but as Guglani goes on to say 'knowledge runs separate to understanding'[1]. The information explosion hasn't led to a knowledge explosion; perhaps even less to an understanding of our brief lives, what matters to each of us and those who care for us and with us. Knowledge needs curating; we believe this journal will be sorely missed for that very reason.

Every healthcare writer should have two objects in mind: one to be true to patients and families, and the other to impart knowledge, ideas and thinking to others (acknowledging Sir Richard Colt Hoare[2] 18th century antiquarian, traveller, historian for inspiration for this sentence).

The *European Journal of Palliative Care* (*EJPC*) has been a place to present well-argued, well-evidenced and thought-provoking knowledge and ideas. In the last nine months as joint editors, we have seen submissions that have stretched the mind, expanded the soul and fuelled the fires of the heart. The use of this metaphor to describe the *EJPC* is no accident. Thomas Carlyle,[3] the 19th century Scottish philosopher, reminded us that the heart always sees before the head can see. From novice authors, to early career researchers to writers of international renown, the *EJPC* has provided an international space to be nudged in our hearts, provoked into thoughtful reflection and called to action in our palliative care practice. As Susan Sontag said 'descriptions mean nothing without examples'.[4]

We thank all the authors, patients and families who have been presented and represented for sharing their wisdom and practice. After all: 'great thoughts speak only to the thoughtful mind, but great actions speak to all mankind'[5] ■

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Avril Jackson
Julie Ling
Avril Jackson manages the EAPC blog and social media activities.
Julie Ling is Chief Executive Officer of the EAPC.

Some relationships can be rare pearls. The relationship between the European *Journal of Palliative Care* (*EJPC*) and the EAPC is one of those. Since the launch of the journal in 1994, we have forged a strong and mutually effective bond. The combined efforts of the EAPC and the *EJPC* have provided our members and readers with a wide range of papers, including several seminal EAPC White papers, and have also published the book of abstracts for many EAPC congresses. We have always welcomed the *EJPC* at our congresses and are grateful for their generous donation of prizes for our award winners over many years.

Another example is our collaboration on the EAPC blog. Launched in 2012, the blog promised to publish shorts post twice a week – from personal perspectives to moving stories and improved care. Enthusiastic – definitely. Over-ambitious – maybe. Sleepless nights planning content – lots!

We quickly decided to build on our links with the *EJPC,* inviting authors to contribute short posts. Since 2012, the EAPC blog has published 761 posts of which 122 related to *EJPC* articles from 22 countries: from Estonia to El Salvador. The diverse and high-quality content has enriched our blog immeasurably. And we've kept our promise to our members and readers to publish the latest examples of good practice in palliative and end-of-life care: from sleep disturbance, to ethical issues in heart failure, to young carers, homelessness, to social media, social work and volunteering ... the list is endless. It's not surprising that four posts relating to *EJPC* articles feature among the all-time Top Ten most-viewed EAPC blog posts. It is also fitting that the most-viewed post of 2017, 'Invasive mechanical ventilation: Concerns over terminal extubation' (da Silva & Tavares de Carvalho) from Brazil, relates to their longer article in the *EJPC*.

Thank you *EJPC* for your precious collaboration over 24 years and for helping people across the world to broaden their skills and knowledge base in palliative care. We are incredibly sorry to see you go.

Look out for more great posts relating to articles in this issue of the journal on the EAPC blog. We also welcome collaboration with new authors – please check out our contributor's guidelines and read past and present posts at www.eapcnet.wordpress.com or contact Avril at avriljacksoneapc@gmail.com ■

The future of palliative care: addressing issues of power through community

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This edition features some important and challenging perspectives on the current predicaments in palliative care – raising questions about where we prioritise our efforts, to what end and how – and all within a context shaped by significant political and economic change and shifts in what people facing end of life want and need.

There is a recurrent theme around power throughout – either helpful or destructive at individual, organisation, system and even national levels. An important question is raised regarding how professionals respond to facilitate a high-quality experience for individuals affected. A recent event organised by the innovation foundation Nesta confirmed how the experience of facing a serious or life-threatening diagnosis was vitally shaped by an individual's sense of power or powerlessness in relation to their illness. Power was retained or regained when people had purpose, could continue to make a difference to others, could control engagement with professionals and services, and were enabled to shape the system of available care. Power was lost when information about a condition, opportunities for expression, or choice on issues considered integral to an individual's identity were denied. The experience of powerlessness was shared by some professionals, particularly when the system denied them the opportunity to make the difference to an individual's life that they believed was important. One contribution stood out for me; a story of oscillating power as the individual moved from healthcare professional to patient and then to participant in a community project. Her power reinstated in her latter role, she enjoys a renewed ambition and passion to make a difference at the end of life. Then there is the question of power within a system, and how changes are best facilitated for communities or populations. Some years ago, I was privileged to be part of a programme of improvement, driven by local people. With leadership from a community development organisation, the community came together to improve the experiences of their communities around death, dying and loss. They began by listening to the stories of people, identifying key themes relevant to the end of life and then talking to the local hospice about how we might work together to address inequalities and shortcomings in provision. I witnessed proactive and sustained efforts on the part of the community development organisation to ensure local people retained power and influence in the process of change. Our meetings were in a venue and at a time of their choice, in participants' first language, the professionals representing only a minority proportion of the group, all focused on an agenda they had generated. The hospice was required to make changes in partnership with community groups, respectful of the role they had played in generating the plan. We saw change; in the profile of those using hospice services and in the development of a strong and sustained community participation programme, of benefit to everyone in the area.

This experience leads to my final thought – how professionals might draw on stronger, sustained community relationships as a means of enabling those in their care to retain power and maximise their sense of agency. A recent evaluation of a community participation programme in end-of-life care confirms the benefits of a partnership between local people and their hospice. Reciprocal relationships established between volunteers and these individuals increases agency and power for all involved. This is made possible by a partnership between an organisation like a hospice that trains and supports volunteers legitimising their role, and local communities who offer time, relationships and commitment to their neighbours, friends and others for whom they perceive a responsibility. The benefits, arguably key to good end of life, include greater wellbeing, decreased loneliness and increased access to palliative care services for those who need them.

This editorial – a blend of personal comment, reflection on experience and learning from research characterises what I have enjoyed most from this journal. It was the home of my first publication and represents a somewhat unique source of information, drawing on opinion and learning through practice, as well as a more rigorous evidence base. I feel privileged to be asked to contribute to its final issue ■

You can read every one of these powerful contributions in a special category dedicated to the *EJPC* at:
https://eapcnet.wordpress.com/category/eapc-linked-journals/european-journal-of-palliative-care/

Transforming a family's end-of-life experience: stopping the trafficking


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Modern slavery and human trafficking is a phenomenon infrequently reported in hospice and palliative care literature. In this case study, **Beth Ward** describes the end-of-life care for a baby from two days to five weeks old and the concerted support for his mother, who the hospice team believed had been trafficked into the UK.

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Over 45 million people are estimated to be trapped in modern slavery across the world with the UK one of the most prominent destination countries in Europe for people trafficking. The current estimate indicates that there are 10,000 to 13,000 potential victims living within the UK, the majority of whom come from, arguably, the poorest countries.[1] Meanwhile, one in five report having come into contact with healthcare services while undergoing trafficking, while one in eight NHS staff in England report that they have seen a victim of trafficking in their clinical practice.[2]

Offences covered by the Modern Slavery Act 2015[3] include slavery, servitude, forced or compulsory labour and human trafficking. Men, women and children who have been trafficked have not given their consent to the move and the process involves elements of exploitation. These fall into a number of broad categories, such as sexual exploitation, forced labour, domestic servitude and organ harvesting. Victims are often in plain sight in the communities into which they have been moved.

Case study

Demelza Hospice Care for Children (Demelza) in the UK provides care and support for seriously and terminally ill babies, children, young people and their families across East Sussex, Kent and South East London. This article outlines the case of Baby F, who was referred to Demelza for end-of-life care at two days of age and received care until his death at the age of five weeks.

Baby F was born at term by caesarean section. His mother had presented late (post-24 weeks) to antenatal screening, at which point tests confirmed that he had a series of life-threatening conditions, including Edwards Syndrome (a genetic disorder also known as trisomy 18) and significant cardiac malformations, as well as spina bifida and talipes.

Baby F's mother was 39 years old and, in the later stages of her pregnancy, lived in temporary hostel accommodation. She reported that she had arrived in the UK from Nigeria approximately five years earlier, and although she had some command of English, her spoken language was Yoruba. The man presenting as Baby F's father, was 26 years her senior and was in employment. From the outset it was apparent that Baby F's mother led a very isolated life; she appeared withdrawn, submissive and hypervigilant, giving the team cause for concern. The team trusted, and acted on, their professional instincts that something was not quite right.

Supporting Baby F and his mother

Baby F's mother appeared especially withdrawn and submissive in the presence of Baby F's father and was very apprehensive and untrusting, with her account of her circumstances frequently changing. She had minimal possessions and no formal papers to confirm her identity. She seemed fearful that professionals would remove Baby F from her and appeared hypervigilant and anxious around new members of the team. Recognising this mother's vulnerability, Demelza's social work practitioner met with her alone and in private, asking only relevant questions and reassuring her that she was safe to speak.

The context of our support

On gaining her trust, it became apparent that Baby F's mother had been trafficked into the UK and had been working in servitude. She reported that she had been orphaned at the age of seven and had been cared for by multiple guardians. She had married 'the King' (the head of her village) and he had arranged for her to travel to the UK. She described the family she worked for as 'not good people'. She explained that they had abused her and she subsequently met Baby F's father while homeless (he offered her his hostel room at night, while he worked). She described that he had no emotional connection to her and she did not appear distressed by his apparent lack of demonstrative warmth or expression of concern for her or Baby F's welfare.

A major challenge for both parents throughout this time was the acceptance that Baby F's conditions would prove fatal. At this time, the baby had already lived beyond expectation (that is, the initial prognosis of days) and their strong faith led them to believe that he would survive. Engaging them in any conversation about the future, therefore, seemed very difficult. In addition, from a cultural perspective, it was very important for the mother to experience motherhood, as this gave her greater social standing within her community, and the father expressed that it was equally validating for him to have a first son.

Despite having Baby F's vulnerability explained to them, there was an increasing risk that the parents would abscond with him, with the journey potentially proving fatal. Based on a 'best interests' principle (a process of discussing and deciding what care is in the best interests of a person if they do not have capacity to make those decisions), the risks were outlined to Baby F's parents and advice on the next steps was sought form the Local Safeguarding Children Board (the term safeguarding denotes measures to protect the health, well-being and human rights of individuals, which allow people – especially children, young people and vulnerable adults – to live free from abuse, harm and neglect). The safeguarding team advised that they could not offer any immediate support while Baby F was being cared for safely by the hospice but recommended that the parents were made aware of the risks and informed that the police would be contacted if they tried to leave the hospice with him. It was decided, at that point, that the police would invoke an Emergency Protection Order (a court order issued for concerns about child abuse), which would then initiate a safeguarding referral. In the meantime, Demelza's team were increasingly vigilant.

Next steps

Having established an understanding of the parents' concerns and legal context of care, it was also recognised that the mother could potentially be returned to destitution or servitude. Post-caesarean section and bereaved, she would be in an exceptionally vulnerable state and, therefore, at high risk of both physical and psychological harm, with a particularly high risk of post-operative complications and/or post-natal depression. Demelza's social work practitioner worked intensively to seek alternatives for this mother via the Local Safeguarding Adults Board (the statutory body to help and safeguard adults with care and support needs) and the No Recourse to Public Funds team. Neither organisation was willing to engage with Baby F's mother, reporting high service demand and the mother's questionable residential status. After an extensive time of seeking support for her, the UK national children's charity, the National Society for the Prevention of Cruelty to Children, recommended the anti-trafficking team of the Salvation Army, a Christian church and charity.

The Salvation Army offered an assessment visit, explaining its role in providing a safe house and supporting the mother in seeking formal asylum status and an exit route from her apparent servitude. It was agreed that Demelza would jointly work with the Salvation Army anti-trafficking team, whose key worker would take over the mother's care at the time of Baby F's death.

During this time, Baby F's health remained very precarious and he experienced prolonged periods of apnoea. As well as focusing on safeguarding this extremely vulnerable family unit, we thought it essential that the mother had the opportunity to bond with her baby and to, albeit briefly, positively experience motherhood. The team worked closely with her, enabling her to gain confidence in caring for Baby F's day-to-day needs, and took photographs at every opportunity. Demelza's art and music therapists supported memory-making by creating parent-and-baby footprints on canvases for both parents and recorded the mother singing lullabies in Yoruba, all of which brought her evident joy as a mother. Given the complexity of her background, formal therapeutic support (that is, in-depth counselling) was not offered, as we felt this may have triggered very difficult memories of grief and loss from her childhood, at an exceptionally vulnerable time.

> “Baby F's mother appeared especially withdrawn and submissive in the presence of Baby F's father and was very apprehensive and untrusting, with her account of her circumstances frequently changing”

Outcome

Baby F died peacefully in his mother's arms at the age of five weeks. His mother's expression of grief was in keeping with her cultural norms; she flayed herself, screaming and crying, until she eventually exhausted herself, falling asleep on the floor. Demelza's social work practitioner and key staff, who had worked closely with Baby F's mother, ensured that she was safe and free to express her grief, while the rest of the team ensured that the other children and families were moved to a quieter area in the building, positively occupied and reassured.

Pre-death planning included clarifying the mother's customs and rituals, which dictated that parents do not attend the funeral of their child, and, therefore, as a mark of respect, a member of Demelza and a representative from the Salvation Army attended.

Shortly after Baby F's death, his mother received a visit from a group of people, none of whom seemed familiar to her. The team recognised immediately that she was at risk of being coerced into leaving with this group and potentially back into servitude. They, therefore, promptly asked them to leave and contacted the team at the Salvation Army. The Salvation Army was able to secure emergency accommodation and a member of the anti-trafficking team collected Baby F's mother later the same evening, accompanying her to a safe house elsewhere in the UK.

Follow-up

A year on, Baby F's mother continues to receive support from the Salvation Army, enabling her to preserve her dignity, reflect, recover and rebuild her life. She is currently living in a safe house and has developed friendships with the other resident women. She has also secured the support of a lawyer and has submitted an application for asylum in the UK. In addition, she is receiving a weekly income and is learning the skills she needs to live independently in the future. Throughout a recent conversation, she expressed her gratitude, suggesting that her words were not enough:

> *'Only God can show you how much you have done for me – you people have taught me so much!'*

Discussion

Baby F received specialist palliative care; his symptoms were well managed, enabling him to die peacefully, in the best possible circumstances.

What did this case teach us at Demelza and what are the lessons it gives for hospices and palliative care in general? First, this case illustrates that modern slavery is present in society, in plain sight, and is a safeguarding issue concerning both adults and children. Given that one in five victims of trafficking report that they have come into contact with healthcare services during the period in which they were trafficked, it is likely that a number of vulnerable people will present in this way, and palliative care teams therefore play an important role in safeguarding vulnerable children and adults.

> "Given that one in five victims of trafficking report that they have come into contact with healthcare services during the period in which they were trafficked, it is likely that a number of vulnerable people will present in this way, and palliative care teams therefore play an important role in safeguarding vulnerable children and adults"

Second, paediatric palliative care is the active total care of a child's body, mind and spirit, while also giving prominence to the child's family. Providing end-of-life care for a baby from the age of two days to five weeks was a complex intervention that focused on child-centred care. In addition to managing symptoms, however, the care of Baby F and his mother also required the team to deal with the complexities of modern slavery, as well as addressing the cultural aspects of dying, death, grief and bereavement. Seeking to identify families' spiritual, religious and cultural beliefs illustrates that paediatric palliative care strives to deliver culturally competent care.

Third, solutions for care and support may come from a range of agencies, as illustrated in this case, in which support was eventually sourced from the Salvation Army's anti-trafficking team. Such multi-agency working has an ongoing role in sharing expertise and resources, thus reducing the risk of duplication of service provision and ensuring sustainability of future services.

Finally, the lessons that children's hospices, and palliative care in general, can learn from this case are to focus on person-centred assessment, trust and act on professional instincts, and understand the legal frameworks within which modern slavery, human trafficking and safeguards operate ■

Declaration of interest
The author declares that there is no conflict of interest.

Acknowledgements
A sincere thank you to Michele King, Social Work Practitioner, Noree Webb, Salvation Army First Responder Co-ordinator, and the Salvation Army Anti Human Trafficking Team, UK.

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Key points

- Trust is fundamental to the success of palliative care interventions.
- Modern slavery is a worldwide phenomenon, with one in five people subjected to human trafficking being in plain sight of healthcare professionals.
- Safeguarding the welfare of the child is paramount; it is important that palliative care teams are appropriately trained and are proactive in recognising and reporting safeguarding concerns.
- Multi-agency working to share both expertise and resources across different organisations is undoubtedly the best way forward, ensuring the sustainability of palliative care services.

Research

The legacy of the Northern Ireland conflict in palliative care

Brendan O'Hara describes a study that examined whether the Northern Ireland Troubles have impacted those working in palliative care, and whether any such impact has implications for the treatment patients receive.

Reconciliation by Maurice Harron was installed in Carlisle Square, Derry, in 1991. The sculpture quickly caught the public imagination and became widely known as *Hands Across the Divide*

BILDAGENTUR ZOONAR GMBH/SHUTTERSTOCK.COM

From 1969 until the signing of the Belfast (Good Friday) Agreement in 1998, more than 3,600 people were killed as a result of violence in Northern Ireland.[1] There has been significant research in relation to the human impact of this conflict, particularly with reference to deaths and on the mental health impact of living with trauma. An estimated 40,000 people were injured as a result of the violence. However, 'comparatively scant attention has been paid to those who survive critical injury. Yet these people often narrowly escape with their lives and often live with long-term disabilities and life-limiting conditions.'[2]

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The impact of the legacy of the conflict (widely referred to as 'the Troubles') on palliative care has received little, if any, previous research focus. This research was undertaken in the context of peacebuilding studies. It was designed to:

- investigate how the legacy of the Northern Ireland conflict may be encountered by professionals providing palliative and end-of-life care
- determine how the distinct context of Northern Ireland has impacted on palliative care practice.

As the impact of the legacy of the Troubles on palliative care has received little – if any – research focus, identification of literature specific to the research area is challenging. Nonetheless, the study provided an opportunity for opening up a dialogue between the disciplines of peacebuilding and palliative care. There is much that these two disciplines share in their concepts and approaches and that they can learn from each other. This view would appear to be supported by the International Work Group on Death, Dying and Bereavement. They suggest that one of the key areas from their experience, with parallels in peacebuilding, is 'recognition of the value of combining science and humanities, evidence and intuition, head and heart, in an inclusive, holistic program that extends across medical, social, psychological, and spiritual realms of discourse'.[3]

> '… it turned out that she was a Catholic who had married a Protestant, and no-one, no-one knew. And she lived in a very loyalist [Protestant] area of Belfast. None of her family … knew. And what she wanted was, she wanted to be buried in her faith'

Study design

The idea for the research project was tested initially with a medical consultant and a nurse, both with significant palliative care experience, working in different provider organisations in the greater Belfast area. Although they were unaware of any research in the area, their response to the research idea was supportive and enthusiastic. The discussions with these practitioners were an opportunity to refine the research topic and interview questions. A qualitative research approach was undertaken to allow for a deeper exploration of an area that would appear to have received little previous research focus. Permission was obtained from the researcher's employing organisation to approach contacts working in palliative care and to recruit a representative sample of participants for interview.

Ethical approval for the study was received from The Research Ethics Committee of the School of Religions, Peace Studies and Theology at Trinity College Dublin in June 2016.

Interviews with professionals

This was a qualitative study with interviews of nine professionals with experience in the provision of palliative care. Participants had experience across a wide geographical area of Northern Ireland, including the region's two major cities, Belfast and Derry/Londonderry, four of the region's five health and social care trust areas, and four of its five inpatient hospice facilities. Participants included three nurses, two doctors, a welfare officer, a social worker, a complementary therapist and a chaplain.

Face-to-face interviews were recorded, with participants involved as members of their professional group or with respect to their experience – and not their perceived community (Roman Catholic or Protestant) background. Their age range was 40–75 years. All of the interviews were carried out by the author and transcribed and analysed using a thematic analysis approach.[4]

The following three themes were identified from the interviews:

- Narratives and Identity
- The Cultural Context of Caring
- Humanising Care.

Within each theme, sub-themes were identified. The Cultural Context of Caring comprises the largest section of research findings and discussion.

Narratives and Identity

Many of the participants reflected on their personal backgrounds, career histories and experiences of patient histories related to the Troubles. They discussed several examples of significant distress experienced by patients that were Troubles-related. Two sub-themes emerged under the theme of Narratives and Identity: personal and professional histories and patient histories.

None of those interviewed had any specific training that referenced the context of working in the Northern Ireland conflict environment. Patient histories recalled provided insight into the context of the working environment. One nurse described sitting down with a woman who had 'very, very difficult pain' and beginning a conversation:

> *'We've been working very hard on managing your symptoms … But I feel I'm missing something here. Because you're not as comfortable as I would like you to be,' and so on. She started to cry. And in the course of the conversation it turned out that she was a Catholic who had married a Protestant, and no-one, no-one knew. And she lived in a very loyalist* [Protestant] *area of Belfast. None of her family – she had sons, daughters – and they had kept it from them. None of them knew. And what she wanted was, she wanted to be buried in her faith.'*[5]

The nurse described how the woman's breathing changed when she was able to talk about the issue causing distress. She 'settled' when she knew that church arrangements could be made that would also protect her family and they 'had to actually withdraw some of the medications'. This case, which happened in the early 2000s, is resonant of the articulation by hospice pioneer Cicely Saunders of the concept of 'total pain', taken 'to include physical symptoms, mental distress, social problems and emotional difficulties'.[6]

The Cultural Context of Caring

While it is known that people are coming into palliative care services with a personal history, and that these histories are extremely important, across the interviews it was indicated that people do not talk about Troubles-related experiences.

A number of reasons for this were identified, including: the pervasiveness and sensitivity around the Catholic and Protestant divide; a culture of silencing, secrecy and denial; it's 'just too difficult'; the implications of disclosure; and a desire to move on from the past.

The reach and impact of the Troubles was set within the context of Northern Ireland being a small community in which people 'have a kind of antennae', where they know 'instinctively' what 'it might not be safe to say'.[7] This 'instinct' plays into the caregiving setting:

> *'For some people, they wouldn't know what fence I sit on and I don't ever disclose that. And I have seen one or two will say, well we'll not talk much about that* [name]*, and I'm not sure how you would feel about that. And sometimes other people can be very vocal on how they feel about the Troubles in Northern Ireland and how that has impacted on them.'*[8]

It would appear that the silencing and denial, which predominated throughout the Troubles, remain a feature of Northern Ireland life. The complementary practitioner recalled, from 2007–2008, a young man with lung cancer 'silencing himself' when they talked about what he thought might have been the cause of his disease:

> *'Exploring a little bit more with me, he told me that he was involved in* [a] *paramilitary organisation at that time, and he was fighting for "the cause", in inverted commas. And I said, is there anything that he felt that he needed support around that, and he says, we'll just leave it there.'*[8]

Silencing could also potentially come from professionals, without the appropriate training and expertise, who will 'block' the conversation 'purely and simply because they don't know how to handle it.'[5] They don't know the right words to say, or they may have been victims of the Troubles themselves and the situation is too difficult for them. There was also an acknowledgement, as this nurse summed it up, that 'maybe some things are just too difficult to talk about'.[5]

A particular concern was raised about the position professionals could be put in by someone disclosing a crime for which they hadn't been prosecuted. One doctor explained how she had encountered people who had been involved in activities either as victims or perpetrators 'who are living with quite painful stories that they feel they can't talk about openly, because they might involve uncovering a reality which hasn't been officially acknowledged'.[7] Any disclosure might also implicate other people in 'lots of things that aren't acknowledged [but] that happened'.[7]

A desire to move beyond the past could have an impact in the caring context. It was suggested that people generally don't want to talk about the Troubles, 'because it almost feels regressive, it's almost like we are in a new phase, why would we be going back there?'[9]

Motivation for not talking about experiences

Patients' reluctance to talk about their experiences could be for a variety of reasons. In her research, Breen-Smyth found that some people living with Troubles-related injury have had to 'manage their identity' and sometimes they didn't want to be drawn into 'awkward, invasive or anxiety-provoking conversations'.[2]

There was also awareness among the professionals of the dangers of opening up conversations without appropriate support being in place, which is resonant of Hayner on the risks of retraumatisation.[10] The complexity of the situations palliative care professionals are faced with resonates with Ledearch's capacity at the heart of transformation, 'which requires us to resist the push to resolve everything rationally into neat, logically consistent packages'.[11]

Humanising Care

In all of the interviews, the distress related to each patient's history was acknowledged, as was their humanity. Two sub-themes are addressed under the Humanising Care theme: Respect for each individual's story and a place of safety.

The importance of a person feeling safe at this time of vulnerability was explained:

> *'Those relationships, and the ability to trust other people, and trust I suppose is the big thing, and to feel safe with other people, is really important in how people die, because you have to be able to trust. And there is sometimes a degree of pain because people find it very hard to feel safe and to trust others, and to be helpless, and to be vulnerable.'*[7]

The professionals' approach to providing good palliative care resonates with many peacebuilding concepts. They are focused with empathy on the individual and displaying 'emotional as well as

> "... people don't talk about Troubles-related experiences. A number of reasons for this were identified, including: the pervasiveness and sensitivity around the Catholic and Protestant divide; a culture of silencing, secrecy and denial; it's 'just too difficult'; the implications of disclosure; and a desire to move on from the past"

cognitive openness, and tolerating the ambivalence that this might arouse’.[12] They see the patient’s point of view without necessarily agreeing with it.

Implications for practice

What the study shows is that the impact of the Troubles has had an effect on the delivery of palliative care, through the attitudes and influences on those who provide the care and those they care for.

The ‘smallness’ of Northern Ireland means that there is little difference between the caregiver and patient in relation to the cultural influences that shape their interaction and ultimately the practice of care. Clark refers to a culture of patients and families and a culture of those who deliver care.[13] In Northern Ireland these may not be easily distinguishable.

> “The ‘smallness’ of Northern Ireland means that there is little difference between the caregiver and patient in relation to the cultural influences that shape their interaction and ultimately the practice of care”

The influences of the religious divide, the silencing and the traumas of the past are not something that the caregiver is apart from; they are very much influenced by them. This has implications for palliative care practice.

Drawing on the cloak analogy in palliative care (from Latin *palliare*, ‘to cloak’), the ‘cloaks’ in Northern Ireland – sensitivities about the Catholic and Protestant divide, the silencing, and restricting opportunities to talk about Troubles-related trauma – could prevent people from having the right care, if the reason for their suffering is hidden. These are ‘cloaks’ that can and do surround both the caregiver and the person needing care.

Key points

- Between 1969 and 1998, more than 3,600 people were killed during the Northern Ireland Troubles and 40,000 people injured.
- This research gives an insight into the impact of the conflict on palliative care practice and the implications as Northern Ireland lives with the legacy of the Troubles.
- The cultural context of Northern Ireland could potentially prevent people from receiving the right care.
- Religious divisions, difficulties associated with addressing trauma, the implications of disclosure, and a desire to move on could be obstacles to addressing personal suffering.
- The palliative care community is well-placed to consider whether the legacy of the Troubles is a factor in the suffering of the people they are supporting.
- A failure to consider the issue could diminish the quality of life of those being cared for.

The research did not set out to quantify the extent of Troubles-related trauma found in palliative care services. The cases referenced in interviews were over a range of time and tended to be those that remained in the memory of the caregiver. There was no suggestion that such cases occur regularly.

Overall, the interviews provided significant insight into the research area. However, a specific question on the topic being researched elicited only brief responses from participants. It is instructive that the limited nature of the responses mostly reflected a difficulty in providing an answer, possibly because the topic hadn’t been given much thought. It is reasonable to ask whether this is driven, possibly unconsciously, by the silencing and denial that is still part of the legacy of Northern Ireland’s Troubles.

Those who took part in the study lived through the Northern Ireland conflict. They have wisdom and experience that a younger generation of professionals could learn from, particularly as they care for people who lived through the worst times of the violence, who are now ageing and are more likely to need palliative care.

The palliative care community should have no fear of asking whether the legacy of the conflict is a factor in the suffering of the people they care for, within the highly experienced and supportive context in which they are providing expert care. The language of legacy, narrative, life story and peacebuilding is one that the palliative care community understands. The bigger risk would be a failure to ask the question, which could diminish the quality of life for those being cared for – those who deserve this quality of life right to the end ■

Declaration of interest

The author declares that there is no conflict of interest.

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What the social sciences have to offer palliative care

Erica Borgstrom, Natashe Lemos Dekker and **Sarah Hoare** describe what social sciences bring to palliative care, outlining three broad types of contribution social sciences make to understanding such care and helping the practice evolve.

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A social science approach to end-of-life care (EoLC) means paying attention to the social context in which the care of the dying, and death itself, occurs. It is about considering the actions of those involved in EoLC, including the patient, their family and healthcare staff, and the social world in which these take place. This approach can be conducted at a micro level – for example, by looking at how individuals speak to each other or by examining the physical environment in which the care takes place – and may incorporate more macro considerations, such as how groups of clinicians interact or the financial pressures on healthcare organisations. Focusing on these factors provides vital understanding of how and why care is delivered as it is and is, therefore, implicit in much EoLC research.

Palliative care, and the end of life more generally, are widely studied themes within the social sciences. Still, the knowledge produced in these studies often remains less visible by the dominant clinical disciplines (medicine and nursing) working in palliative and EoLC. With this article, we seek to highlight some of the contributions made from a social science perspective, and demonstrate what we can learn from these in palliative care.

Overview of social science engagement with palliative and EoLC

The care of dying persons has been a topic of social science exploration for decades. Most notably gaining momentum during the 1960s, 1990s and the current decade. Concepts derived from in-depth social science research are now regularly considered to be core elements to an understanding of EoLC, both within the social sciences and for those practising EoLC. Examples of such groundbreaking concepts are Glaser and Strauss' 1965 description of awareness,[1] Seale's 1998 notion of dying scripts,[2] and Kellehear's 2005 concept of public health palliative care to enable more community involvement.[3]

Many social scientists working on EoLC research today are part of interdisciplinary teams whose research may use theories and methods commonly used in the social sciences, but the team publications do not often contain in-depth discussion of the implications of their work for sociological or anthropological theories. As such, the contribution of social sciences becomes less visible. This seems in part due to the pressures of publishing in medically oriented journals that often require shorter articles, and therefore less space for theoretical discussions. In our experience, the research published in social science journals, which enables longer discussion, tends not to be taken up by EoLC policy in the same way as research in medically oriented journals or previously mentioned 'seminal' pieces.[1–3]

To explore this, the Open University in the UK hosted a workshop in November 2017 on researching EoLC from social science perspectives. The purpose of the event was to bring together a range of social scientists – primarily sociologists and anthropologists – working on and in EoLC research to consider our collective contribution to this field and future directions. Twenty academics from around the world, who are at various stages in their careers, attended this workshop for two days of intense discussions about both their individual research projects and the wider implications of our work. This event was supported by a workshop support grant from the Foundation for the Sociology of Health and Illness, and additional funding has come from the Association for the Study of Death and Society, two organisations that support research into EoLC and death more generally.

But why do we need an event to talk about the social science perspectives of researching EoLC? Or even an article in this journal to highlight this perspective? Too often, the fields of palliative and EoLC are thought about in terms of the practical medical and nursing care provided to dying people. As societies seek to improve the quality of care provided during this time of life, there is an opportunity to look at the wider social context of what the end of life is like and what it could be like. We distinguish three kinds of contributions that social science perspectives currently bring to EoLC research that we wish to highlight in this article.

Dying as a social process

Social scientists consider dying to be a social process.[4] This means that we recognise that dying involves people, practices and places, and that it is not just something that happens to the body. This understanding of death is reflected in how determining the timing of death has changed over time and with advances in technology.[5,6] In terms of EoLC, viewing dying as a social process also helps us appreciate who else is involved, and how their involvement is shaped by social expectations. For example, research has examined the role different professionals have when helping someone understand that they are dying, and how this is a key transition within EoLC.[7] Furthermore, what death means is influenced by cultural norms and expectations about dying. To understand EoLC, then, also means having to unravel the cultural processes, values and meanings that are at play in death and dying.[8]

Social scientists are trained in studying and understanding these different aspects of the social process of dying and making sense of them in their cultural contexts. The research discussed at the workshop came from a range of countries – the UK, China, Switzerland, Belgium, the Netherlands and Australia. Looking across different cultural and country examples enables us to identify patterns and values that resonate across such boundaries and ones that are more particular to specific places. Although there is the cliché that everyone dies – it is not true that everyone dies in the same way or that we all derive the same meaning from death. A social science perspective about EoLC illuminates this diversity.

> “To understand [end-of-life care] … means having to unravel the cultural processes, values and meanings that are at play in death and dying”

One facet of social science research is that it seeks to understand things in their context – recognising how, where and when something occurs impacts how and why it occurs the way it does. For example, social scientists have sought to unpack current policy and practice interest in preferred place of death. Asking patients where they want to die is recommended practice in many countries, and their answers are used to influence policy and direct the care people receive. Kristian Pollock, who has a background in anthropology and has carried out qualitative research in a range of healthcare settings, has highlighted that the research around preferences for place of death are problematic.[9] This is because preferences vary over time, depending on the patient's previous experience, who is caring for them and what support is available. Moreover, some patients may not have a preference, or place of death may not be a priority for them. Some of our own research has contributed to this debate by highlighting how problematic stating preferences and choices can be and yet how choice operates as a mechanism for service delivery.[10,11] What this growing body of social science research shows us is that not only is preference of place far from universal or straightforward, but also that we need to be critical of how such ideas shape the process of dying.

The use of stories

Some social scientists are particularly interested in people's stories and experiences – this can be about their care, their deaths and ultimately about their lives. There are some similarities with narrative medicine, which uses stories to promote healing. Collecting, listening to and connecting with these stories and narratives reminds us – both as researchers and as fellow human beings – that there is more to dying than a 'failing body' being treated by doctors. Instead, dying is often a very intense time of living for all involved, for a variety of reasons. Many of the popular books about EoLC feature narratives of care,[12,13] and many accounts about EoLC by social scientists analytically examine people's narratives to find common patterns or to highlight particular issues.

Each of this paper's authors has used stories in different ways in their own research in order to understand palliative and EoLC in a variety of contexts. For example, Borgstrom recorded the everyday lives of people who could be in their last year of life and has retold their stories of living, family life and decision-making in order to look at how people make sense of their lives in the context of EoLC.[14] These stories have not only been used to critique current policy on choice in EoLC[10] – they have been instrumental in creating case studies for teaching about death and dying. Hoare talked to ambulance staff, GPs, hospital clinicians and family members in order to understand how EoL hospital admissions occur, using their narratives to recreate a history of a patient's admission. These admission histories showed that hospital was important in the care of patients, providing an important nuance to current conversations in which hospital is typically dismissed as a poor site of EoLC.[15] Lemos Dekker studied the experiences of people with dementia, their family members and professional caregivers in nursing homes in the Netherlands. This allowed for an in-depth understanding of the normative conditions and values that inform care at the end of life for those with dementia.[16] The methods social scientists use – including in-depth interviews and ethnographic approaches – and the ways in which we share our work can make these experiences more recognised, both within the field of EoLC research and more generally. Social scientists use material such as patient, family and caregiver narratives not as anecdotes but as a basis to theorise about life and death.

Applied social sciences

Some social scientists take a more explicitly applied approach to their work on palliative and EoLC, such as the workshop's keynote presenters, Profs. Jane Seymour and Allan Kellehear. In different ways, both have sought to ensure that their research findings have direct practical relevance to improving care by collaborating beyond their discipline and outside academia. Prof. Seymour, for example, has conducted research for, and with, charities and non-government agencies in order to translate findings into interventions that can be used in clinical practice.[17] Similarly, the public health approach to palliative and EoLC has both been made prevalent by, and is a product of, work conducted by Prof. Kellehear.[3,18]

'Applied' projects seek primarily to generate knowledge that can be used to improve practice. Projects might involve co-developing tools, spaces or even models of care with patient groups, clinicians and other professionals – all the while attending to issues of representation, power dynamics and how things are made meaningful.

> "'Applied' projects seek primarily to generate knowledge that can be used collaboratively to improve practice. This might involve co-developing tools, spaces or even models of care with patient groups, clinicians and other professionals"

But even in these spaces where the use or impact of the social sciences may be more visible, academics working in this field can often feel misunderstood or marginalised. So part of our discussions at the workshop have also been about the practicalities and implications of collaborating with others – sharing tips and reflections from our previous and current projects. This included the importance of explaining to, and even learning with, collaborators some of the key concepts that we are working with in our research, including explorations about home and good death.

Conclusion

German–American psychologist Kurt Lewin (1890–1947) is noted for saying that 'if you want to truly understand something, try to change it'.[19] Through careful analysis, critique and reflection, our endeavour to understand care at the end of life is also an attempt to change it – to change the way such care is currently carried out, experienced or framed. Each of us at the workshop comes to this topic with a different perspective and ambition, yet a shared sense that social science perspectives on EoLC can make a contribution to this field ■

Declaration of interest
The authors declare that there is no conflict of interest.

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Workshop information
More about the workshop can be found on Twitter, using #SOCSCIEOLC, and on our event website:
www.open.ac.uk/health-and-social-care/main/researching-end-of-life-care

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Key points

- ☐ Social sciences can contribute much to palliative and end-of-life care research, both in terms of theories and methods.
- ☐ Dying is a social process – social sciences can help us understand this process.
- ☐ Stories and narrative approaches can be used to illuminate complexity and care.
- ☐ Social science research can be applied to inform practice and policy.
- ☐ It is useful to recognise the value of social science contributions to end-of-life care policy and practice by learning about how social science makes sense of the world.

UK ambulance services: collaborating to provide good end-of-life care

■ **Sarah Stead, Shirmilla Datta, Claire Nicell, James Hill** and **Richard Smith** explain the initiatives set up in two UK ambulance services that have resulted in improved education on end-of-life care among paramedics, using a collaborative approach that is beginning to have an impact at national level.

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Over the last ten years, the role of NHS ambulance services has adapted considerably, in line with the changing needs of the wider healthcare system. With the evolving priorities in the NHS of managing an increasingly ageing and complex population in the community, ambulance services in the UK now not only play a crucial role in the delivery of urgent and emergency care, but are also required more frequently to provide care in the home and in community settings.[1] This role has been previously outlined in the 2008 *End of Life Care Strategy*[2], in NHS England's *Urgent and Emergency Care Review*,[3] launched in 2013, and in the 2014 *Five Year Forward View*,[4] which recognise that ambulance services are key to the NHS in providing patients with the 'right care, at the right time, in the right place'.[4]

In England alone, approximately half a million people die each year, and this number is expected to rise steadily over the coming years.[5] Around three-quarters of deaths are 'expected', rather than sudden, and these individuals should receive high-quality end-of-life care (EoLC). It is thought that this high-quality care can be delivered by non-specialist health and care staff as part of their core work; however, this relies on staff having adequate time, education, training and support.

EoLC, and staff education on the subject, have become priorities for ambulance services as a result of increasing patient needs and the desire to be able to provide patients with care in the place of their choosing, which is often in a community setting. There is a need to improve the care provided, regardless of the place of death or the personal and medical circumstances of those concerned; therefore, ambulance services, along with other healthcare providers, are taking action to help people plan and prepare for death.[6] Historically, the role of the paramedic has been driven towards the preservation of life at all costs. The idea that ambulance services can support a patient to experience a good death, in their place of choosing, which is often not the acute hospital, requires a major cultural shift. Education on EoLC and palliative care is vital in helping ambulance clinicians feel confident in supporting a patient as they reach the end of their life, and working closely with hospices and community palliative care providers is key to this.

Ambulance clinicians often find themselves responding to patients at the end of their life with very limited information about the patient. They are relied upon to make difficult and time-critical decisions – for instance, about whether to transport someone to hospital – often with little support or advice.[7] The *End of Life Care Strategy* (2008)[2] discussed collaborative working between different services and how this can lead to improvements in EoLC provision and the National End of Life Care Programme (2012)[7] recommended that there are opportunities for joint education and training between both ambulance services and specialist EoLC providers.

Few studies have sought to understand how often ambulance services attend EoLC patients. A study by Munday *et al.*[8] found that 33% of ambulance staff estimated that they care for a terminally ill patient at least once every shift, with 29% suggesting this could be once every two shifts.

An emergency call may be made for an EoLC patient for many reasons. Common examples include an unexpected crisis, patients becoming distressed or family members having difficulty in accessing a normal care pathway.[9] While the role of ambulance services in EoLC was previously underestimated, they are now widely recognised as a crucial part of EoLC provision in the community.[10]

Until 2016, very little, and often inconsistent, education or training on EoLC was provided to paramedics and other ambulance clinicians. Although this is now provided to all undergraduates and features on many internal training courses, the lack of training has historically led to a lack of competence and confidence among ambulance clinicians in managing this complex group of patients. A study by Kirk, for example, while limited in its findings, highlighted that ambulance clinicians felt that

■ **Ambulance clinicians are increasingly finding themselves called upon to act quickly in responding to a patient's end-of-life needs while having very little or no information about the individual**

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they had a lack of knowledge around EoLC and feared litigation or persecution by their employer or the Health Care Professions Council if they made a wrong decision.[11]

Collaborative working in two UK ambulance services

1. East of England Ambulance Service NHS Trust collaborations

Across the East of England Ambulance Service NHS Trust (EEAST), a number of successful collaborations with community providers and hospices have been undertaken, leading to some large steps forward in equipping staff with a good level of education and support.

In 2016, a paramedic, Smith, in one area of the trust approached a local hospice, the Hospice of St Francis in Hertfordshire, and set up a one-day workshop for ambulance staff, which covered topics that included recognising a dying patient, advance care planning, communication skills, 'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)' decisions, palliative emergencies, symptom control and signposting. These workshops are now held every six months and over 100 members of staff in this area of the trust have attended them. This training has also since been replicated with other hospices across the east of England, with nine hospices having supported or currently supporting the delivery of EoLC training to ambulance clinicians.

In addition, the Hospice of St Francis works with the local university, where hospice staff members, together with two EEAST paramedics, provide EoLC education to all third-year undergraduate paramedic students, who also have a two-day hospice placement.

Organisational back up is vital to underpin collaborative working and improve education. In April 2017, the EEAST three-year EoLC strategy was launched, which has five strategic aims and outlines key objectives for improving EoLC provision across the trust. At the end of Year 1, the objectives have been largely achieved and, across the trust, staff now have access to a mobile directory of services, which provides them with phone numbers for palliative care providers and hospices throughout the trust. All internal training programmes for new starters at the trust now include a short EoLC training session, while the yearly mandatory update programme, which covers every member of staff, now also contains an EoLC section. In addition, the trust's e-learning platform now has a dedicated EoLC program, bought and adapted from the South East Coast Ambulance Service NHS Foundation Trust (SECAmb). This is available to all operational staff.

A bimonthly EoLC focus group is held within the EEAST and is attended by a wide range of staff of different grades and from different areas of the trust. The group is also supported by external colleagues, including community EoLC leads, hospice educators and medical directors. This collaborative style of working has proved very successful and allows for excellent discussions and developments. Expert opinion has formed a vital component of these developments, including the creation of an EoLC flow chart to support staff with decision-making.

In April 2017, the trust held an EoLC focus month. Daily updates and articles were shared, mainly via the electronic rolling newsletter. These included a DNACPR 'frequently asked questions' paper, an update on 'just in case' medications, a day in the life of a clinical nurse specialist, podcasts on recognising dying patients, and articles on paperwork in EoLC and having difficult conversations. A highlight of the month was a Facebook Q&A session. This involved a two-hour evening slot in which participants – both internal staff and the public – were invited to ask questions about EoLC to a panel of experts, namely the trust EoLC lead and two colleagues from the Hospice of St Francis. This was highly successful, with many topics covered and many questions raised and answered.

> “A study by Munday *et al.* found that 33% of ambulance staff estimated that they care for a terminally ill patient at least once every shift, with 29% suggesting this could be once every two shifts”

The trust actively engages with the wider healthcare system, including with those who commission care within the area, community teams and EoLC providers.

Early indications suggest paramedics and other ambulance staff are recognising patients nearing the end of life more readily. They are asking for help and support more often, and those hospital admissions deemed to be avoidable at the end of life are slowly reducing. The electronic patient care records show an increase in the numbers of patients recorded by clinicians as requiring palliative care or EoLC, and early evidence indicates a better than average non-conveyance rate to emergency departments, suggesting some of the education and support is helping. Calls to hospice helplines have increased as staff recognise the need to find out more information about a patient before acting and making a decision.

2. South East Coast Ambulance NHS Foundation Trust collaborations

Prior to 2015, the strategic focus and awareness of the impact of EoLC provision on the ambulance service were minimal across the SECAmb. An improvement project was developed; it was dedicated to EoLC and focused on education, integration and collaboration of the ambulance service with the EoLC community and improving access to information. This was managed by one of the SECAmb's clinical leaders and is now a full-time role within the clinical development team.

Education

The EoLC Lead has worked with local hospices, universities and within the trust to begin to standardise education for ambulance clinicians. This began with the development of an e-learning program, which was marketed to two other ambulance services, and has since developed into a large programme of continuous professional development sessions available to clinicians across the SECAmb area, facilitated either by the EoLC lead or in conjunction with hospices.

Reciprocal education has also been provided to hospices, focusing on the role of the ambulance services, breaking down barriers and improving understanding of roles and responsibilities across the system.

In addition, the EoLC Lead works with all universities in the area to provide standardised education around EoLC, which is now part of the core programme for new paramedics joining the trust. A substantial amount of time has been allocated for mandatory training, which all clinical staff will undergo in the year 2018/19, specifically covering the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process, recognising dying, and recognising the last year of life.

Integration and collaboration

The trust works closely across the 22 local healthcare commissioning groups to provide a consistent approach to EoLC from a SECAmb viewpoint. This has helped to share learning across the system, as well as to identify best practice and address any issues.

As described previously, the EoLC lead works closely with hospices in the area, which generates reciprocal arrangements around EoLC that are beneficial across the system.

Information sharing

The SECAmb works closely with specialist providers throughout the area in order to share information about the most vulnerable and complex patients, using an internet-based system known as IBIS (Intelligence Based Information System). This is updated by specialist care teams and accessed by crews on scene in order to inform decision and facilitate shared decision-making.

The ambulance service also holds key documents, such as DNACPR decisions received from care teams, to ensure that decisions about patients' care are upheld.

Quality EoLC is a key focus for the SECAmb, and it is widely recognised that good end-of-life experiences have a significant impact not just on patients but also on their families, as well as staff and the wider healthcare system.

National ambulance service collaboration

After acknowledging the lack of standardisation in EoLC in the ambulance service, the SECAmb lead worked with the Association of Ambulance Chief Executives to create a group to share learning, create a community of practice and develop consistency of approach across the country.

The group meets twice a year and maintains contact in between those meetings. This group has had a significant impact through joint-working on national e-learning projects, sharing of key policies and guidelines, and updating and providing input into the EoLC guidance developed by the Joint Royal Colleges Ambulance Liaison Committee, which produces national guidelines for all UK ambulance services.

> “While the core basis of paramedic training remains focused on saving and prolonging life, it is vital that the profession continues to develop and acknowledge the need to enable patients to receive care in line with their wishes and best interest”

Conclusions

Significant progress in EoLC provision has been made among UK ambulance services in recent years, following recognition of the role this group has in managing patients approaching the end of life. While the core basis of paramedic training remains focused on saving and prolonging life, it is vital that the profession continues to develop and acknowledge the need to enable patients to receive care in line with their wishes and best interest.

This article has discussed the progress within two UK ambulance services and the first stages towards a consistent approach across the UK. While this demonstrates an excellent start, it is important that this momentum is maintained and the approach continues to develop. We believe that continued collaborative working of ambulance trusts with hospices and other EoLC teams will help ambulance clinicians to deliver effective, compassionate and relevant EoLC ■

Declaration of interest

The authors declare that there are no conflicts of interest.

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Key points

- With the changing priorities in the NHS of managing an increasingly ageing and complex population in the community, ambulance services are increasingly required to provide care in community settings, including for patients needing end-of-life care (EoLC).
- Education on EoLC is vital to help ambulance clinicians feel confident in supporting patients who reach the end of their life, and working closely with hospices and community palliative care providers is key to this.
- The East of England Ambulance Service NHS Trust (EEAST) has undertaken a number of successful collaborations with community EoLC providers and hospices, while one of the hospices works with EEAST paramedics and the local university to provide EoLC education to paramedic students.
- The South East Coast Ambulance Service NHS Foundation Trust (SECAmb) has developed an improvement project, dedicated to EoLC and focusing on education, integration and collaboration of the ambulance service with the EoLC community, and improving the access to information.
- These collaborations, as well as work to share learning, create a community of practice and develop consistency of approach across the country, and have led to significant progress in EoLC provision among UK ambulance services in recent years.

Creating a legacy – a tool to support end-of-life patients

Carolina Vidal, Ana Luísa Gonçalves, Marta Pavoeiro and colleagues explore the concept and creation of a legacy explaining the techniques and benefits – both physical and spiritual – for both patient and carer/family.

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Palliative care aims to provide whole-person care by relieving pain and other distressing symptoms, integrating psychological and spiritual aspects of patient care, which enhance an individual's quality of life.[1] The least practiced interventions are those in existential and psychological suffering despite being highly valued by patients.[2,3]

The term legacy and its clinical use in psychosocial interventions had not been widely adopted in the palliative care literature until recently.[4] Creating a legacy is not a routine practice in palliative care units, although it is a recognised way of addressing the existential and spiritual issues that are so important in the overall suffering of the end-of-life patient.

As healthcare professionals in a palliative care unit, we are confronted daily with the proximity of death. With few exceptions, people facing the possibility of imminent death wish their lives to have purpose and meaning. Healthcare professionals are, therefore, faced with the task of providing assistance with an individual's spiritual concerns, and helping them to achieve greater tranquility and inner peace.[5]

Creating a legacy in end-of-life patients

Legacy activities help individuals and their families initiate a life-review process that results in a product that can be enjoyed before and after the person dies. There is evidence that creating a legacy can help in the management of physical and existential symptoms.[6,7] Legacy activities also improve a sense of well-being and can ease the process of grief.[7] It is the very process itself that is therapeutic, allowing the patient to live better in the present and promoting a 'legacy that is lived' instead of only creating a 'legacy that is left behind' for others.[4]

There are several lines of work with end-of-life patients that cannot be confused with legacy but that support the achievement of a legacy work. During legacy activities, we can suggest topics to highlight the focus and content of that person's legacy: the things that were most appreciated in life; the most important people in the individual's life; how they will be remembered and the ideas, books, poems or songs that influenced their life.[6]

Relatives can also participate in the task, if that's the patient's wish. Families can give their contributions, adding significant memories and experiences that can be combined with the individual's. Trained volunteers, occupational therapists, psychologists, social workers, doctors and nurses can help patients create a legacy. A person who the patient trusts should be a facilitator in the life review and in the search for meaning. The key is to be an empathic and compassionate presence with the ability to listen, select and highlight key messages, frame facts and help in the resolution of conflict.[8]

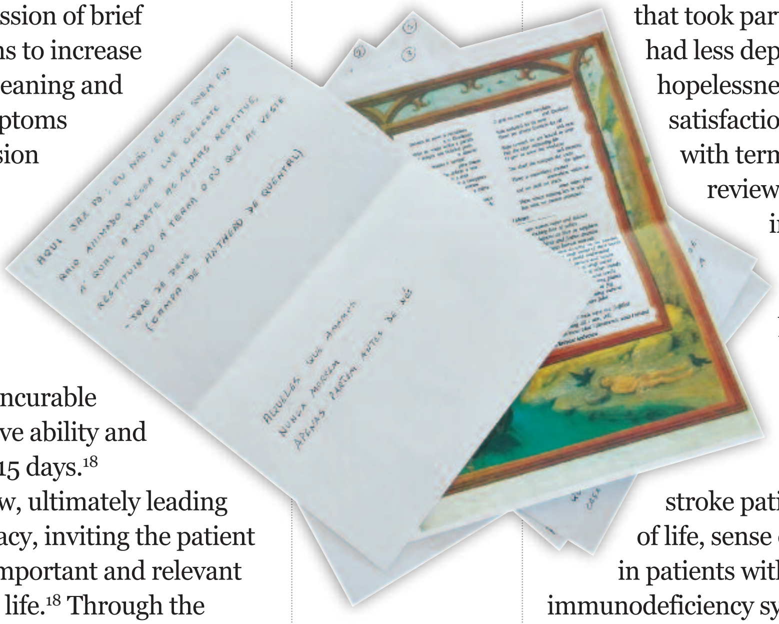
It is uncertain as to when the work of creating a legacy should be best performed, to avoid any negative impact on the therapeutic relationship and patient's well-being. Most dying patients react well to the proposal of a legacy work, when properly presented and framed. There may be a window of opportunity and it should not be left too late in the disease process. The facilitator should have flexibility and persistence and be able to adapt to the patient's energy and rhythm.[8]

Some patients may surprise the facilitator by their willingness and ability to speak, and may spend hours describing their experiences.[8] It will be this collaborative capacity of patients that will determine the number and duration of sessions necessary to perform the legacy work.

Framing aspects of legacy: life review and Dignity Therapy

Healthcare professionals who help patients share their life stories are aware of the positive impact this work can have on their lives.[8] Legacy work has a conceptual background in both life review and in dignity therapy.

Life review is an adaptive and constructive process and refers to a process of social significance and cultural sharing. It can invoke memories of both pleasant and painful experiences.[9] The recall of past events as a therapeutic intervention was first proposed by Butler who defined it as a natural and universal process of recalling ancient experiences as a strategy for the resolution of past conflicts.[10,11] Life review had previously been associated with harmful effects perhaps causing mental deterioration. It was, therefore, discouraged.[12,13] Butler was the first to recognise it as a constructive and adaptive technique. Life review as a technique can be used to promote adaptation to the various phases of life[14] in a preventive perspective, stimulating the intellectual and cognitive skills of elderly people with dementia,[15] limiting the impact of posttraumatic situations[16] and minimising social isolation.[12] Life review can also support the process of grief[17] and alleviate depressive symptoms.[15]



■ **Figure 1.** The simplest form of legacy document, a letter allows the expression of feelings, emotions, experiences, memories, and the passing on of wisdom and advice

Dignity therapy (DT), introduced by Chochinov[18] is a psychotherapeutic intervention that consists of a single session of brief psychotherapy, which aims to increase an individual's sense of meaning and purpose. It improves symptoms such as anxiety or depression and increases self-esteem and feelings of hope about what is possible in the context of a serious illness. It is intended for people with chronic, progressive and incurable diseases who have cognitive ability and life expectancy of at least 15 days.[18]

DT enables a life review, ultimately leading to the elaboration of a legacy, inviting the patient to speak about the most important and relevant positive moments of their life.[18] Through the suggested points, the therapist will contribute to restructure the thoughts of the patient. The interview is recorded in audio format, the dialogue is then converted into a transcript and a legacy document created. Finally, the document is returned to the patient and will be shared with the individuals the patient has chosen.[18]

Evidence of legacy benefits

There are few clinical trials that have studied the effect of building a legacy in palliative care as an isolated intervention. Most of the evidence comes from studies that include the construction of a legacy, such as DT but which are part of more comprehensive interventions.

DT has been shown to be effective in reducing physical suffering and depressive symptoms, and increasing the will to live in terminally ill patients, as well as restoring their notion of dignity, purpose and sense of life.[18]

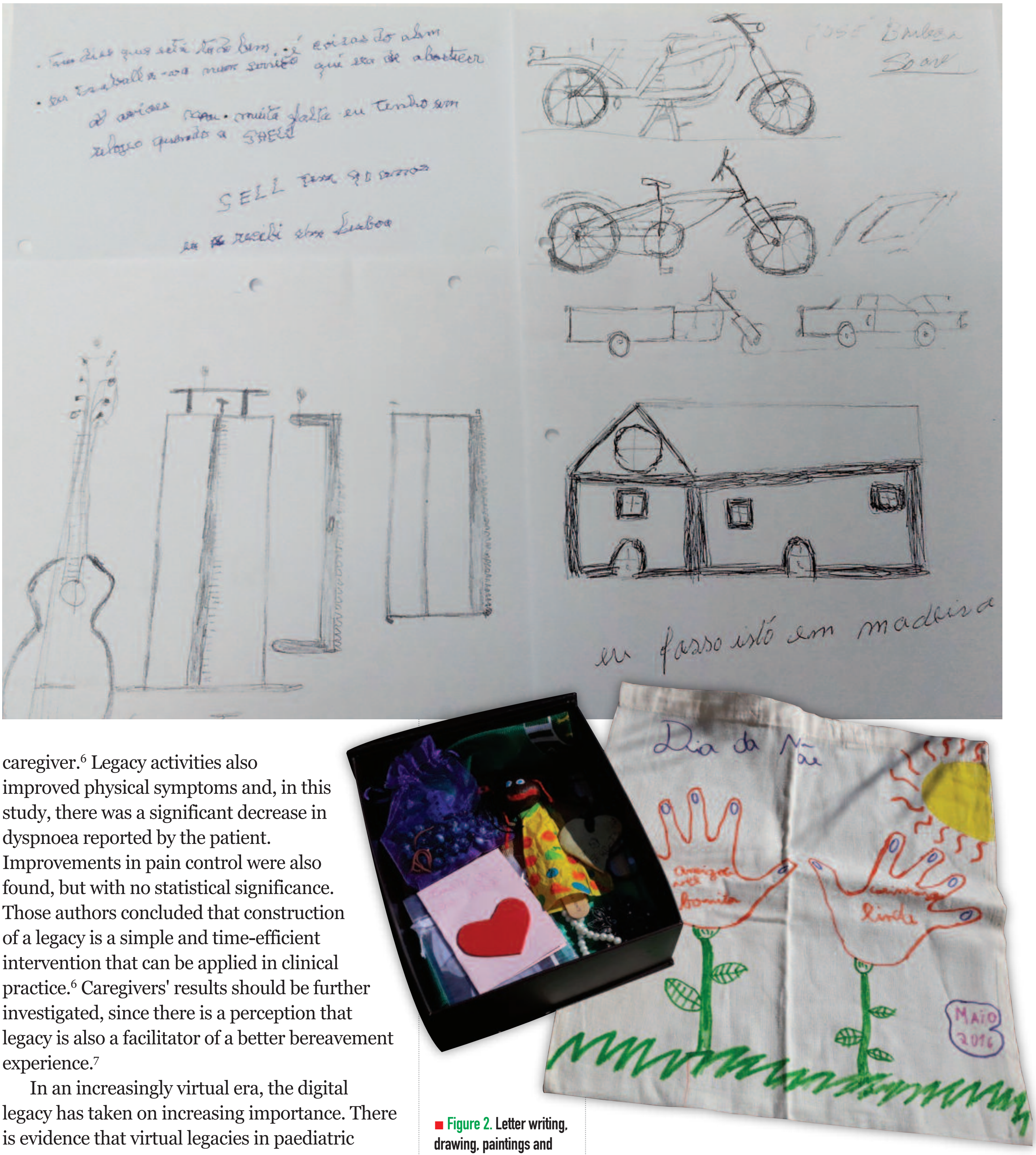
A Portuguese study, found that DT improved symptoms of depression and anxiety in end-of-life patients, with the therapeutic effect maintained over 30 days.[19] Julião and colleagues also concluded that patients who received DT were less demoralised, had a reduced wish to hasten death and a significant reduction in 19 items of the Patient Dignity Inventory.[20] Unlike other psycho-socio-spiritual interventions, DT has high levels of acceptance and satisfaction. However, there are limitations about this intevention that are recognised in the studies, regarding patient recruitment and retention.[3,21]

Life review, a subtype of brief psychotherapy, also describes an intervention to alleviate existential and spiritual suffering.[21] The positive effects of this intervention were evaluated by Serrano and colleagues[22] in a study that included 43 patients with depression. The group that took part in a therapeutic life review had less depressive symptoms, less hopelessness and higher levels of life satisfaction. In another recent study with terminal cancer patients, life review caused significant improvement in spiritual well-being, anxiety, depression, suffering and happiness.[23]

A recent systematic review[7] summarised that life review is effective in reducing depression in stroke patients[24] and increasing quality of life, sense of purpose and self-esteem in patients with acquired immunodeficiency syndrome, decreasing depressive symptoms in this population.[25] Recently, the therapeutic life review was recommended as a non-pharmacological treatment of depression in end-of-life patients.[26]

Vuksanovic and colleagues compared DT with life review, in order to isolate the additional therapeutic effect of creating a legacy object or document. This study showed significant improvements in the sense of generativity and ego-integrity in the group of patients who received DT.[3] This suggests that the unique process of creating a legacy that transcends death itself has therapeutic effects for the patient, reducing anxiety and depression. These authors conclude that beyond high levels of patient satisfaction, families and caregivers also benefit from the creation of a legacy.[3]

Allen and colleagues evaluated the impact of creating a legacy on palliative patients.[6] This study showed that creating a legacy induced a significant improvement in caregivers' stress, increasing social interaction between patient and caregiver, as reported by both patient and the



■ Figure 2. Letter writing, drawing, paintings and other art forms are all examples of legacy documents, allowing the creator to communicate and express feelings and memories. A legacy box (bottom left) gathers meaningful objects selected by the patient and stimulates life review

caregiver.[6] Legacy activities also improved physical symptoms and, in this study, there was a significant decrease in dyspnoea reported by the patient. Improvements in pain control were also found, but with no statistical significance. Those authors concluded that construction of a legacy is a simple and time-efficient intervention that can be applied in clinical practice.[6] Caregivers' results should be further investigated, since there is a perception that legacy is also a facilitator of a better bereavement experience.[7]

In an increasingly virtual era, the digital legacy has taken on increasing importance. There is evidence that virtual legacies in paediatric palliative care increase emotional comfort for parents and improve communication between the child and parents.[27]

Duggleby and co-workers studied the psychological processes underlying the promotion of hope in elderly patients with advanced cancer receiving palliative care.[28] They concluded that in this model of hope, four specific processes were included: reminiscence, leaving a legacy, positive appreciation and motivation processes. Legacy activities can, therefore, also help in the conservation and restoration of hope.

Examples of legacy activities

Legacy can be constructed and incorporated in very different ways: writing, voice recordings, films and more physical and tangible ones, such as objects or paintings.[2] An oral recording is an easy way of creating a legacy, it can include video or audio, to which can be added clippings from newspapers, photos, poetry, works of art, music, etc. Creativity imposes no limits on what can be achieved as the final product.

In our daily practice, there are several examples of legacy interventions, such as the creation of a photo album. A collation of photographs capturing emotions, moments, people, important life events journeys and places that depict the essence of that person's life.

Writing a letter is a simple form of legacy, through which the patient can communicate experiences, wisdom, virtues and future advice (see Figure 1), as is drawing (see Figure 2). The realisation of an autobiography is another example of a legacy work. Creating a film, music or a poem are other forms of legacy that we have witnessed. Examples such as the creation of crochet shoes for a baby, a notebook for the first year of schooling for a grandchild. or a family cookbook are more examples of legacy interventions.

The realisation of the so-called 'tree of life', in which the patient places in each branch the people they have found most meaningful in their life, is also a form of legacy activity practised in some units of our country.

Another way to work on legacy is the creation of a box containing meaningful objects (see Figure 2), photos, letters or even amulets selected by the patient. The act of gathering these objects stimulates life review and the construction of a physical legacy full of meaning that survives the individual and can help the process of grief. Digital social networks can also be used by patients to build virtual legacies.

Conclusions

We encourage teams to adopt legacy activities because they are clearly aligned with the objectives of palliative care. Beside the psychological impact, there is also increasing evidence that creating a legacy alleviates physical symptoms, which further validates these interventions.[6]

Creating a legacy stimulates life review and helps the patient to discover meaning, reconcile conflicts and regrets, remember moments of private happiness and prepare for the end of life in a peaceful and creative way ■

> "... the unique process of creating a legacy that transcends death itself has therapeutic effects for the patient, reducing anxiety and depression"

Key points

- We encourage teams to adopt legacy activities because they are clearly aligned with the objectives of palliative care.
- The construction of a legacy is a simple and time-efficient intervention that can be easily applied in clinical practice.
- Creating a legacy can help in the management of physical and existential symptoms.

Declaration of interest

The authors declare that there is no conflict of interest.

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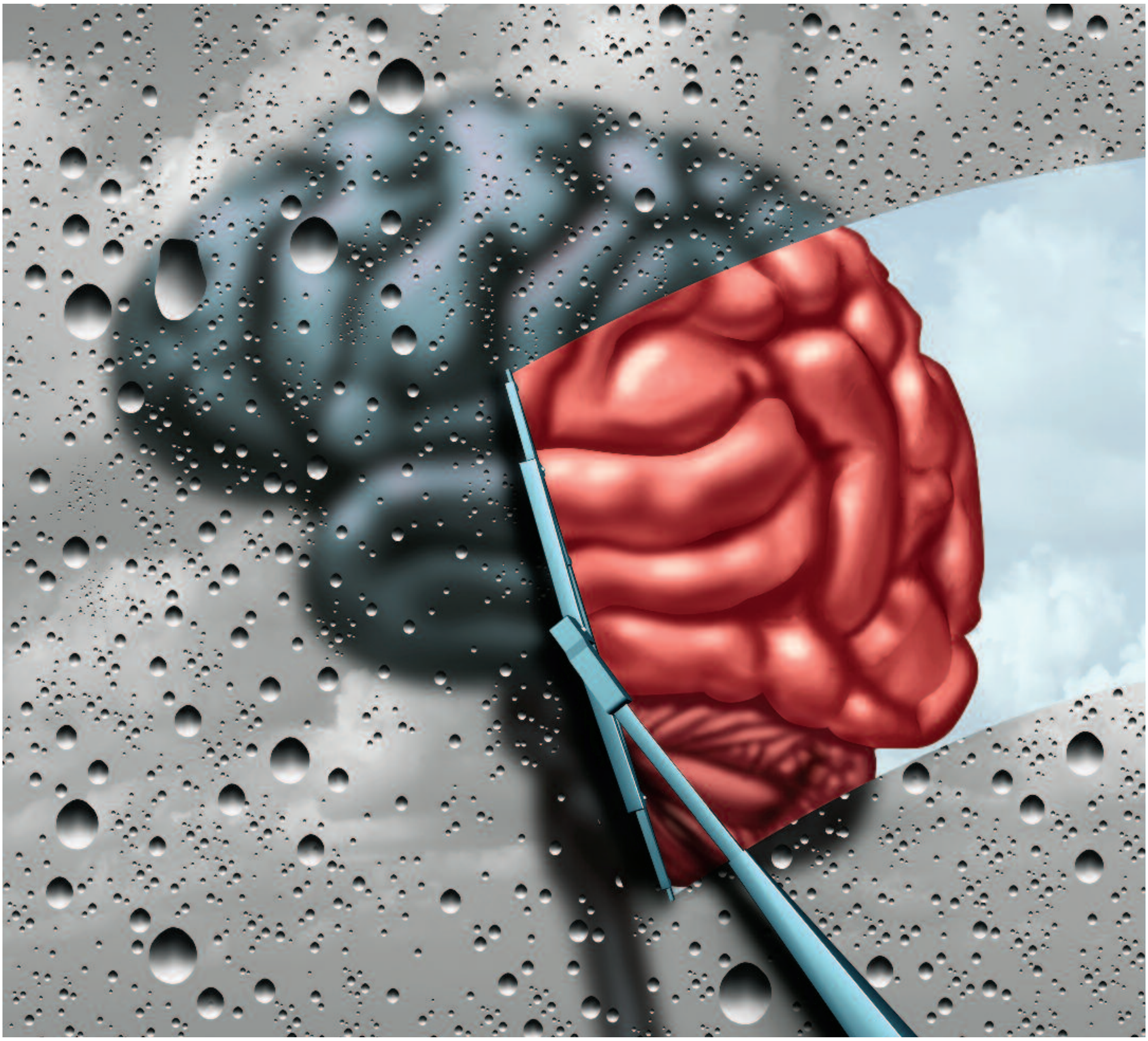
There is growing recognition in the palliative care community of the emotional and psychological needs of patients – and their carers – as they reach the end of life. But not every patient needs, wants or has access to formal contact with a psychologist. What's more, all members of a multidisciplinary team are likely to experience the impact of psychological matters in their daily practice with patients and colleagues, whether or not their role is to explicitly address those. This series of articles aims to summarise some of the 'big ideas' in psychology and translate them into practical advice to promote psychologically informed practice for those providing palliative care, whether as doctor, nurse, allied health professional or in any other clinical or non-clinical role.



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Psychological ideas in palliative care: distress, adjustment and coping

Many patients, family and staff use the word 'traumatic' when discussing end-of-life experiences. As with many terms we have considered in this series, 'trauma' and 'traumatised' mean something more specific in a clinical sense than they do in common usage. What does it mean to be traumatised, and how might we recognise and manage this condition in a palliative care setting?

What is a trauma?

Historically, what counted as a trauma was quite narrowly defined. A person had to be directly affected by an event in which there was actual physical harm – or the very real threat of it – that was outside the normal range of human experience. This might include being involved in an act of terrorism, or conflict – indeed trauma is the contemporary way of understanding what was known as 'shell shock' in the First World War and 'battle fatigue' in the Second – or a particularly horrendous accident. In the present day, while academic researchers sometimes require exposure to an objective threat – for example, death, serious injury or sexual violence – in order to make a diagnosis, those of us working clinically tend to regard any situation in which someone subjectively experiences extreme fear, helplessness or horror as having the potential to traumatise. Hence, it is possible to be traumatised by events in which there was no actual threat of harm, such as following a bomb scare that turned out to have been a hoax; and childbirth is a statistically very common experience that sometimes leaves mothers traumatised for a variety of reasons.

Recent literature makes helpful distinctions between types of trauma. We speak about 'simple' trauma, which arises after a one-off event such as a car accident, and 'complex' trauma, which arises after prolonged or repeated experiences, such as being subject to domestic abuse.[1] We also speak about 'intentional' events, which have been deliberately brought about, such as a robbery, as opposed to 'non-intentional' events, such as an earthquake, for which no one is responsible.[2] Of particular importance in a healthcare setting, we have also begun to recognise that people can be traumatised indirectly – sometimes known as vicarious or secondary trauma – either by witnessing or hearing in detail about another person's trauma. For example, it can happen that a paramedic becomes traumatised by what they witness while attending the scene of a serious car accident; or a lawyer may be traumatised by hearing the testimony of a rape victim.[3]

Sadly, events such as these are not outside the range of normal human experience. A recent global review found that more than 70% of us will be faced with something potentially traumatising during our lifetime – the most likely experiences being witnessing a death or serious injury, the unexpected death of a loved one, being robbed, being involved in a serious car accident or having a serious illness or injury.[4] Most people will have an intense physical, emotional and behavioural response after such an experience (see Box 1). When that experience is prolonged and disrupts someone's functioning, they may be diagnosed with post-traumatic stress disorder (PTSD). Mental health difficulties in adulthood may be related to trauma experienced in childhood (see Box 2).

Box 1. Post-traumatic experiences

Experiences following a traumatic event typically fall into three clusters:[5]

Intrusive thoughts and memories

The person is unable to keep thoughts of the event from their mind. They may be reminded of it by tangentially related triggers, or thoughts may arise seemingly at random. They may have intense and vivid intrusions, such as flashbacks or nightmares, or they may feel compelled to go over and over the event (rumination). They may have difficulty concentrating on other tasks or feel that they have 'zoned out' of the present moment (dissociation).

Hypervigilance and arousal

The mind and body remain in threat mode, poised to detect and respond to further threat. Senses may feel heightened. The person may be jumpy and easily startled, with an intense physical reaction to even 'minor' triggers. They may be agitated or irritable. They may feel that they are constantly scanning or 'on guard', and their sleep and appetite may be disturbed.

Avoidance and numbing

The person may try to avoid reminders of the specific event by directly avoiding locations, people or activities associated with it; they may also avoid depictions of similar events in the media. Avoidance may take the form of throwing themselves into other activities. They may also try to avoid strong emotions in general by distancing themselves in relationships or using alcohol or other substances to 'numb' themselves.

To warrant a diagnosis of post-traumatic stress disorder (PTSD), these experiences must persist for more than a month after the event and be intense enough to cause significant distress and/or impair role functioning.[6]

Box 2. Childhood trauma

The term 'childhood trauma' encompasses several different adverse experiences:

- childhood emotional and physical neglect
- child sexual abuse (one-off event or chronic)
- child physical abuse (one-off event or chronic)
- child emotional abuse.

Each of these events can have the impact of severe trauma on a child and can be related to other mental health problems, such as depression, anxiety disorders, eating disorders and post-traumatic stress disorder, later in life. Higher proportions of people who have experienced childhood trauma are found in psychiatric populations. Childhood trauma is known to play a part in lower tolerance of stress and interpersonal difficulties in adulthood. Recognising the impact of childhood trauma can help in understanding what factors might be playing a part in mental and emotional distress in adulthood.[7]

A review of longitudinal studies of responses following a potentially traumatising event,[2] found that one month after the event, an average of 29% of people were experiencing symptoms of PTSD, while one year after the event this had reduced to 17% – indicating that for around one-third of subjects the symptoms had resolved. This is a significant number of people, but it is still a minority. Why is it that some people come through a potentially traumatising event or experience and are traumatised, while others are not? One part of the answer lies in the way that the event is processed in the brain.

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Trauma and the brain

The following explanation contains significant oversimplification. Readers interested in further detail may find Deborah Lee's *Recovering from Trauma using Compassion Focused Therapy*[8] a useful resource.

We often think about memory as being like a recording device that takes in everything and plays it back exactly as it was. It's not. What matters to us massively influences what we pay attention to and thus encode. This is why two people who took the same walk may remember it very differently. How we feel massively influences what we can recall. This is why when we are angry we can remember every annoying thing someone ever did.

Memories of events in our life – such as brushing our teeth this morning – are called episodic memories. Ordinarily these are processed in quite a comprehensive way. Information is taken in through our senses and passes through the amygdala – a centre of emotional processing – to the hippocampus. In the hippocampus, key features get 'tagged' to help link them to other experiences, and the memory gets 'time-stamped' before it is stored in a part of the brain that links easily to language. This means that when the memory is accessed, either by a reminder cue (such as seeing a toothbrush advert) or because we're consciously trying to remember ('Did I brush my teeth?'), we can not only recall the event, but we can place it in time, link it to other memories and tell the story fluently: 'I brushed my teeth after I got dressed, and I noticed we were low on toothpaste so I put it on the shopping list.' This sort of remembering is not usually an emotional experience, though we may remember the emotion we felt at the time: 'I was annoyed because I meant to buy toothpaste last week.'

Memories we make when we are under intense stress – sometime called trauma memories – are different. When the brain is in threat mode, information is processed in the amygdala. It doesn't get passed to the hippocampus, so it doesn't get tagged or time-stamped effectively. This means that trauma memories can be linked to or triggered by unexpected things, and they often take the form of a sensory experience (being in 'threat mode') rather than a 'story'. They can feel as though they are actually happening again – sometimes in a jumbled-up way – rather than being remembered. This process can feel intrusive and intensely frightening. People may go to significant lengths to avoid any triggers of traumatic memories. At other times they may feel compelled to go over and over them trying to make them 'make sense' or gain control over them.

Box 3. Psychological interventions for trauma

Psychological interventions for trauma typically involve three phases,[11] although they may differ in how explicit they are about each phase and how much emphasis they place on each:

I. Safety and stabilisation

Ensuring that the person is protected from further trauma. For example, it is unhelpful to treat someone for the trauma of domestic abuse if they are still living with their abuser. Once they are safe, helping them to develop strategies for managing their hypervigilance and arousal, for example by encouraging lifestyle changes, and training them to use relaxation and self-soothing techniques.

II. Exploration

Using a therapeutic setting and careful pacing to support the person in reducing their avoidance of intrusive thoughts of the trauma, and in beginning to remember and reflect on the experience and the impact it has had on their lives (using the strategies from phase I to manage any distress that arises).

III. Integration

Supporting the person in connecting or re-connecting with the relationships and activities that they may have been avoiding, with a view to them regaining a meaningful life in spite of what happened to them.

Table 1. More and less helpful ways of talking about trauma to patients

Less helpful	More helpful
• You've been through something really difficult. Do you want to talk about it? • **Oh my god, that must have been awful. I don't know how I would have coped with something like that.**	• You've been through something very difficult. Can you help me understand how that affects you now? • **How often do these happen for you? Do you notice any patterns or triggers? Is there anything that you've found helpful?** • It sounds like those memories you're having are like flashbacks. Memories of trauma can be different because of the way our brain deals with information when we are under intense stress.

Some people – perhaps because they have had training or experience in coping with potentially traumatising events (such as service men and women) or because they have low baseline stress levels, effective emotional regulation and other coping strategies, or supportive relationships – may be able to process the traumatic experience relatively normally during or shortly after the event.[9,10] They may remember the event as terrifying and difficult, but it is a memory not a re-experiencing, and it happens at predictable times and/or in a manageable way. They may avoid ever getting into a similar situation again, but they don't feel a need to avoid anything and everything that might remind them of it. Other people may need more time or support – including psychological therapy – to complete that process.

Why is all this relevant to palliative care?

Recognising and responding to the effects of trauma are particularly important in a palliative care setting. This is because illness and end of life may have directly exposed patients and family to traumatising experiences:

- Amar has frequent flashbacks to the moment that his doctor told him that his condition has turned out to be not diverticulitis, as thought, but incurable bowel cancer.
- Beth underwent a pleural drain insertion that was complicated and extremely painful. She becomes overwhelmed by panic at even the thought of visiting the hospital again, and she avoids the television for fear of scenes of medical procedures.
- Camille was horrified to witness her husband coughing up a huge quantity of blood. She hasn't been able to sleep well since – she finds she is listening to his breathing.

Alternatively, some features of a patient's present situation may consciously or unconsciously retrigger memories and symptoms of a former trauma:

- Douglas found that the sounds and smells of the hospital during a recent acute admission reminded him of his last hospital admission, following a motorcycle crash in his youth. He has started having nightmares about the crash, even though he has rarely thought about it for many years.
- Eleanor is bedbound in a hospice during the last days of her life. She finds the feeling of helplessness and the reassurances made by the nurses – 'Ssh, calm down', 'This won't hurt' – take her back to her experience of childhood sexual abuse.

Looking after a traumatised patient: how can we use these ideas to help?

If we encounter patients for whom these ideas seem relevant, how should we respond? Formally diagnosing and treating PTSD should be attempted only by someone who has the appropriate training and support. Depending on the impact of the patient's symptoms and their prognosis, it may or may not be appropriate to pursue that on their behalf. Whatever our role though, it is possible to behave in a manner that is sensitive and supportive.

Talk around the trauma, not about it

Ordinarily, when someone has been through a difficult situation and it seems to be on their mind, our urge is to make the time and space for them to talk about it. That may not be helpful in the context of trauma. Encouraging people to talk about their traumatic experience when you don't have the setting or skills to be able to contain their distress is likely to trigger further memories and escalate distress.

You also run the risk of secondary trauma: being distressed yourself by exposure to the patient's story. Your emotional response may then in turn affect the patient. Patients will be acutely sensitive to the impact of their story on those they tell it to. If your responses indicate that you are frightened, disgusted or angered by their experience, you may – inadvertently – add guilt and shame to their emotional burden.

That is not to say that you should shut all conversation down. You can talk about the current impact of the experience and show understanding and empathy without going into the details (Table 1). It may be helpful to talk to the person using the language of trauma or even provide brief literature. Cwm Taf University Health Board has a downloadable 'Stabilisation Pack' that offers helpful basic information and guidance.[12]

Support the patient with 'grounding' strategies

It (almost) goes without saying that we should be mindful of a person's unique triggers – sounds, smells, environments and so on – and do our best to limit their exposure to them. If a person seems to be preoccupied with their traumatic experience, or even to be re-experiencing it, resist the urge to engage with the specifics of the story. Try instead to use verbal and non-verbal cues to show that you recognise and understand how they feel. Experiencing empathic communication is in itself useful for reducing threat mode.[13]

Then try to gently redirect their focus onto something calmer and/or more positive in the here and now. Your aim is to help them to realise that they are 'here', and the threat they faced is not a threat just now. One patient liked to sing, for example; another found being taken to the window and having a conversation about the garden below to be calming. Try to avoid leaving the person to choose an activity themselves – 'What else could we do just now?'. In threat mode, the person's creativity and recall are impaired, and if they're not able to engage, it may increase their anxiety and make them more vulnerable.

You may have to be quite directive about this, clearly interrupting a narrative and moving the topic on. That will probably feel quite uncomfortable, but it's the right thing to do. Share among the staff group topics or strategies that you found to be effective.

Consider the relationship with medications

Medications – particularly strong painkillers or anxiolytics, but really any medication that may affect a person's alertness or perception – can be tricky for people with symptoms of trauma. Some

> "... trauma memories can be linked to or triggered by unexpected things, and they often take the form of a sensory experience (being in 'threat mode') rather than a 'story'. They can feel as though they are actually happening again – sometimes in a jumbled-up way – rather than being remembered"

may have an intense fear of feeling 'woozy' or 'out of control'. This might be because it is a direct trigger of the past trauma: perhaps they sustained a head injury, were under the influence of a substance or were treated with similar medications at the time of the trauma. Or it may be because they fear that that state will make it harder for them to 'control' thoughts and memories of the trauma that they have been avoiding. They may find even intense pain or other potentially treatable symptoms preferable to taking that risk. They may refuse medications without a clear awareness of why, or without wishing to discuss it, which can be frustrating for us when we wish to alleviate their suffering.

Other patients may use medication as a numbing or avoiding strategy, finding that the same 'wooziness' helps them to manage thoughts and memories. These patients may use or request more of such medications than an objective evaluation of their symptoms would indicate, which can also be frustrating for us.

In either case, initiating a gentle and non-judgemental conversation is appropriate: 'I've noticed something about the way you use your painkillers. I linked it to something you told me about what happened to you. I may be putting two and two together and getting five, but I wonder if we could talk about it?' The person is not being difficult; they are trying to find a way of being that causes them least suffering. If we can address any preconceptions or alter any prescriptions to support them to do that, we should do so. Sometimes continuing as things are is really the best path, but it's helpful for all involved to understand what the situation is and why.

> " ... try to gently redirect their focus onto something calmer and/or more positive in the here and now. Your aim is to help them to realise that they are 'here', and the threat they faced is not a threat just now "

Traumatised staff

You may have perceived already that professionals working in a palliative care setting are vulnerable to trauma for the very same reasons as their patients. Their work may expose them directly to various traumas – a particularly challenging death, for example, or being subjected to periodic episodes of aggression or violence – or it may connect with traumas from other times or areas in their lives. One author, Laura van Dernoot Lipsky, has written eloquently about the less intense but more chronic trauma of simply coming into contact with other people's pain and suffering every day of our professional lives.[14]

Good staff management, a compassionate workplace culture and explicit reflective practice are ways in which staff can be protected from the potential effects of trauma they might experience.[14,15] If you recognise some of the signs and symptoms discussed here in yourself, though, it is very important that you seek additional support, and treatment if you need it. It is tempting to 'keep on keeping on', but there is a fine line between minimising avoidance and chronically exposing yourself to re-traumatisation. In this, perhaps more than any other circumstance, we owe ourselves and our colleagues the same compassion that we offer our patients ■

Key points

- **Potentially traumatising events are very common over the course of a lifetime. Many people will experience some degree of intrusive thoughts and memories, heightened arousal and avoidance after such an experience.**
- **Where these experiences persist, post-traumatic stress disorder may be diagnosed.**
- **Palliative care patients may have been exposed to trauma directly by their illness or treatment, or past difficulties may have been retriggered.**
- **We can deal sensitively with the impact of trauma on our patients, without engaging in intensive or specialist treatment.**
- **It is important to reflect on and protect our own emotional safety when working with this patient group.**

Declaration of interest
The authors declare that there is no conflict of interest.

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STOP! Patients receiving CPR despite valid DNACPR documentation

■ **Lucy Baxter, Jennifer Hancox, Ben King, Alexandra Powell** and **Thomas Tolley** examine the circumstances in which eight patients with valid Do Not Attempt Cardiopulmonary Resuscitation forms in their medical notes nonetheless received cardiopulmonary resuscitation.

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Although cardiopulmonary resuscitation (CPR) can be life saving in the arrest scenario, there is increasing recognition that it is not always appropriate and, at times, may cause harm. Making appropriate Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions, can help avoid unnecessary suffering and uphold dignity in death.[1,2] Anticipating scenarios where CPR is inappropriate and documenting these decisions helps healthcare staff and resuscitation teams focus care effectively. Decisions need to be documented and communicated clearly, so they can be recognised by all healthcare staff involved in patient care.[1] This is particularly important in the acute setting, with a resuscitation team who may not be familiar with the patient.

In the UK, there are a variety of Treatment Escalation Plan (TEP) documents which are regularly updated based on new research and guidance.[3] A TEP is a clinical decision tool to document and plan care for an acutely ill or deteriorating patient. This trust utilised a purple combined treatment escalation form with an additional yellow sticker indicating 'Do Not Attempt Cardiopulmonary Resuscitation' if the patient was not suitable for CPR. This form would be placed in the front of the medical notes, to be easily visible for all staff.

In the event of patient deterioration, any healthcare professional could seek support from the resuscitation team. CPR is one component of resuscitation in an unwell patient and in many cases is not required when a resuscitation call is made; a patient may be successfully resuscitated with other measures such as fluids and oxygen alone.[4] Therefore, it may still be appropriate for a call to be made for patients with a documented DNACPR decision.

But, what happens if, despite valid DNACPR documentation, an individual receives CPR? This goes against the patient's best medical interests (as agreed with the patient and their medical team) and often their autonomy and family wishes.[1] There is very limited published research into analysis of circumstances where this has happened, although the 2012 NCEPOD (National Confidential Enquiry into Patient Outcome and Death) 'Time to Intervene' report, which reviewed cardiac arrest cases across multiple trusts in the UK, detailed that 52 out of 552 (9.42%) patients had CPR despite valid DNACPR documentation. No data were collected to try to establish why this occurred.[5] This study analyses cases of CPR delivery despite valid DNACPR documentation within the trust, to identify areas for improvement.

Method

Retrospective analysis of medical and nursing notes

Patients in a 1,034 bed acute trust[6] were identified who had both a resuscitation call put out and a valid DNACPR form in their medical notes. Those who received CPR despite DNACPR documentation in 2014 were included for analysis. Data were collected using a predetermined data collection form designed to identify patient demographics (including Dalhousie Clinical Frailty Scale[7]), contributory factors surrounding the making and communication of the DNACPR decision and the set of circumstances leading up to delivery of CPR.

Results

The total number of resuscitation calls made within the trust in 2014 was 457, of which 132 were for cardiac arrests.[8] Eight of these received CPR despite valid DNACPR documentation (6.06% of CPR cases).[1] A further patient was excluded from analysis as CPR had commenced on transfer from community to hospital.

The eight patients

- Mean age = 83 (range 76–92)
- Mean Dalhousie Frailty Score[7] = 6 (range 4–9)

- Specialties responsible for care: Care of the Elderly, Stroke, Oncology, Gastroenterology.

Documentation of a DNACPR decision in the medical and nursing notes

A TEP form (including DNACPR decision) was present in all cases (see Table 1).

- One set of notes was unclear as the medical notes entry read 'For now for resus' but was accompanied by a treatment escalation form indicating DNACPR, but referral to the Intensive Care Unit in the event of patient deterioration
- One set of medical notes indicated the patient was dying, but there was no explicit reference to DNACPR
- None of the medical or nursing notes detailed if the decision was relayed to other healthcare team members.

The resuscitation call

Documentation of the resuscitation call for each case was analysed, and data were collected on the timing of the arrest call relative to the patient's admission and DNACPR decision, as well as the time from last consultant review and last notes entry prior to arrest (see Figure 1).

Analysis

Patients included in this study consisted of the older and frailer patient population. The time from DNACPR decision to arrest and from admission to arrest was very variable but, in most cases, there was adequate time to make (mean – 7.4 days) and communicate (mean – 4.6 days) these decisions.

Similarly, the last notes entry (mean – 19 hours) and last consultant review (mean – 1.5 days) prior to arrest were also variable, making the impact of these difficult to interpret.

In 75% of cases, the decision was explicit in the medical notes, although few cases documented a discussion with the patient or relatives. No notes documented whether the decision had been relayed to other members of the healthcare team and in only one case was the DNACPR decision recorded in the nursing notes. This indicates that the documented communication around the decision is poor and there is limited recorded evidence of discussion with patients, relatives or nursing staff.

In one instance, there was evidence that moving the patient contributed to inappropriate CPR as the call was put out by the radiology team, who were unaware the patient had a DNACPR form. There is insufficient further data regarding patient ward moves as influencing factors, as these were not always recorded in the notes.

Table 1. Documentation of acknowledgement of DNACPR decision/ discussion with patient and relatives

	Yes	No
DNACPR recorded in medical notes?	6	2
DNACPR recorded in nursing notes?	1	7
Record of DNACPR being discussed with patient?*	3	5
Record of DNACPR being discussed with relatives?*	2	6

*1/8 discussions with patient and family were documented in the community and copied into the medical notes

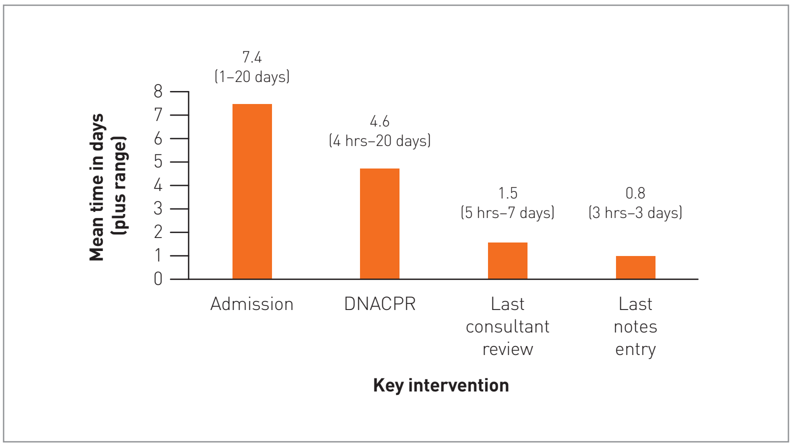

Figure 1. Mean time from key interventions to arrest

Limitations

As there is no historical precedent for this type of study, there are no immediate comparisons to be made. Due to the small sample size, no in-depth statistical analyses were possible. A standardised data collection form kept collection bias to a minimum.

Conclusions and recommendations

The total number of resuscitation calls made within the trust in 2014 was 457, of which 132 were for cardiac arrests.[8] Eight of these received CPR despite valid DNACPR documentation (6.06% of CPR cases), which appears similar to national statistics on this topic (9.42%).[5] It is not possible to draw strong conclusions from a small sample size, but it appears that documenting decisions and ensuring their dissemination across the healthcare teams and settings is a key area for improvement.

It is unclear if the difficulty in communication is from decision maker to the wider team or from continued handover. All instances occurred in the context of a resuscitation team that did not know the patient and therefore the emphasis is on making the escalation plan clearly visible and ensuring that ward staff are aware, so that in a time-pressured situation, the appropriate management is delivered.

More recent guidance following legal cases and statutory changes, has further highlighted the importance of timely decisions, communication and documentation relating to CPR decision-making.[9] An improvement in this communication could potentially be achieved by including TEPs (including DNACPR) in nursing and doctor handovers. Furthermore, decisions and documentation should take place within the context of patient and family wishes and understanding. Additional sections on the TEP form, providing space to document discussions with patients, relatives and other healthcare professionals, may also improve appropriate delivery of care. Interestingly, documentation of discussions about DNACPR decisions and escalation plans with patients and family was identified as an area requiring improvement by the Care Quality Commission for this trust in 2015, although in 2017 the trust had improved and were rated highly for this.[6]

Systematic reviews have highlighted the importance of handover and effective documentation to ensure continuity of care during inter-hospital transfers.[10,11] This study identifies that handover of TEPs is relevant not just between wards, but also when attending other departments such as imaging or outpatients. Medical notes should be transferred with the patient and a TEP placed in an agreed section of the notes, normally at the front, to be referred to in an emergency. The addition of a standardised handover plan may make this information even more accessible.

Given the paucity of published research on this topic, a comparison of similar reviews in other trusts may identify themes that could be tackled on a larger scale. Further research could explore potential barriers to communication around CPR – for example: time limitations, discomfort in making these decisions and uncertainty regarding the law. This trust has recorded 21 further incidents between January 2015 and May 2018 in which patients received CPR despite valid DNACPR documentation in place, demonstrating this is still an ongoing concern and that the messages from this study remain relevant.

Performing CPR despite valid DNACPR documentation opposes basic ethical principles of beneficence, non-maleficence and often patient autonomy. By seeking to increase communication around this decision and subsequent awareness, future cases could be avoided ■

Declaration of interest
The authors declare that there are no conflicts of interest.

Author contributions
All authors have had equal contribution in the design, data collection, analysis and conclusions drawn from this study. As co-first authors, Lucy Baxter and Jennifer Hancox were the main contributors to the writing of this report.

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Key points

- Performing CPR despite valid DNACPR documentation opposes ethical principles of beneficence, non-maleficence and autonomy.
- Eight patients were identified as receiving CPR despite valid DNACPR documentation in 2014.
- A significant lack of documented communication between healthcare staff and patients/relatives was noted.
- Including DNACPR decisions on medical handovers, adapting treatment escalation forms and education around communication of this decision may reduce these instances.
- Further research could focus on barriers to communication and similar studies in other trusts.

Point of view

The relevance of 'total pain' in palliative care practice and policy

■ **Marian Krawczyk** and **Naomi Richards** propose that a decades-long lack of inquiries into the concept of total pain, since it was devised by Cicely Saunders in the 1960s, has led to a knowledge gap and disparity in understanding between clinicians, and that a deeper understanding of total pain is a priority for the evolution of palliative care practice and policy.

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Cicely Saunders first used the term 'total pain' in 1964 to describe the intertwined physical, psychological, social and spiritual dimensions of pain.[1] This radical departure from the previous understanding of pain as purely physical provided a new interdisciplinary concept that transformed medical understanding of suffering. This concept was also critical in forging the specialty of palliative care. As 2018 is the centenary year of Cicely Saunders' birth, this seems a particularly apt time to re-engage with total pain as one of her most enduring legacies and to consider its contemporary relevance.

Further consideration of total pain seems both timely and necessary. Palliative care is promoted globally as the gold standard for end-of-life (EoL) care (EoLC),[2] but this foundational concept has undergone virtually no in-depth examination on how it has evolved or how it is understood and addressed in different clinical and cultural contexts. In this paper we aim to begin this conversation. First, we briefly outline key issues in defining total pain and consider some professional and system-based challenges to addressing total pain. We then suggest how the substantial knowledge gap around total pain has potentially serious consequences in clinical practice and policy development. We end with a review of some of the research questions about total pain that we believe need answering in order to inform practice and policy initiatives.

Defining total pain

Saunders championed two clinical interventions to address total pain and proactively ensure that the manifold challenges in dying did not develop into intractable suffering. The first used a conventional medical model of pain to focus on pharmacological expertise in analgesics to prevent – rather than just alleviate – physical pain. The second involved clinicians eliciting and attending to patients' experiences of illness, including their emotional, social and spiritual distress.[3] To accomplish this, Saunders advocated a particular set of emotional labour skills, whereby 'listening has to develop into real hearing'.[3] Addressing total pain, therefore, requires a therapeutic relationship that attends to physical symptom management and also to patients' subjective experiences, narrative and biography. This holistic orientation, and resulting specialist care practices, became known as 'total care' or 'whole person care'.

Importantly, this holistic orientation was not only for the benefit of patients and their family. Saunders argued that this way of caring required clinicians be willing to attend to, and create meaning from, their own suffering that arises as a byproduct of witnessing that of others.[4] In order to be resilient in the face of total pain, clinicians need more than just the 'technique' to competently address physical pain – they also need a philosophical orientation that makes sense of suffering, lest it result in 'staff pain'.[4] Consequently, while Saunders' concerns about total pain were centred on the individual dying patient and their family, she also believed that a patient's unresolved suffering affected everyone in the care relationship and demanded a particular therapeutic response.

In spite of the centrality of total pain as a guiding concept in the development of palliative care, discussion about what it actually means has been extremely limited. Within critical social theory, total pain has been identified as: an orientation that has the potential to both empower and constrain patient behaviour;[5] a descriptor of troubled clinician–patient relations;[6] a way of 'mystifying' the specific origins of suffering;[7] and a form of narrative medicine that highlights the irreducibility of pain.[8] While each of these perspectives provides significant insights, they have neither been integrated into the clinical literature nor used in policy.

The handful of clinical publications devoted to exploring the concept of total pain empirically do so through individual case studies. Although the concept is commonly referenced elsewhere in the literature, it is more often 'quoted' than defined in any detail and primarily appears in nursing or allied health journals. Similar to other descriptors of palliative care, a curious circularity seems to exist in trying to define total pain, whereby definitions often reference other equally poorly defined terms.[9,10] Clinicians acknowledge that this lack of clarity challenges their ability to both define and address their patients' suffering.[11,12] Is total pain best defined and understood as a care philosophy, a descriptor of personal experience, a relationship or a set of clinical practices? Is it even limited to end of life? This definitional confusion is further exacerbated by the expansion of palliative care, and by the organisational complexity and resource constraints that define today's healthcare systems.

Contemporary challenges

Research indicates a growing discordance between the ideals of palliative care and the reality of providing EoLC within increasingly complex and resource-constrained healthcare systems.[13,14] Expanding the scope of palliative care in terms of diagnosis and illness has had both intended and unintended consequences. Concerned clinicians highlight how the mainstreaming of palliative care has brought significant benefit, while requiring a 'fit' within present-day system dynamics that focus on physical symptom management.[15,16] As a result, addressing the complex aetiology of suffering that early palliative care clinicians understood as central to their practice may be marginalised or structured as a pharmacological problem to be solved. A biomedical framing can, even within interdisciplinary teams, result in expressions of suffering becoming the responsibility of specific professions, such as part-time social workers and pastoral support workers, rather than being the 'bread and butter' of daily practice for all clinicians. This division of labour, however, may also reflect the reality of EoLC versus the ideal upheld by Saunders. After all, her professional training was highly unusual, spanning nursing, social work and medicine, and giving her unique insights and a holistic skill set that few other clinicians have.

Current challenges may also be a legacy of the concept originating within the historical context of a relatively controlled space (the hospice) with respect to a specific disease (cancer) and prognosis (predictable decline near the end of life). With the expansion of the specialty into generalist, acute and disease-specific categories (and now even palliative rehabilitation), clinicians are engaged in a variety of disease trajectories and with patients who may not have been told, in clear language, that their disease is progressive and terminal and who may still be seeking curative therapies. Many are now living longer with multiple morbidities, albeit in more fragile and uncertain states of health, making it increasingly challenging to understand when a patient is nearing the end of life. Clinicians are also providing care in radically different healthcare systems now, defined by complexity, fragmentation and resource constraints. In these contexts, even palliative care clinicians are required to adopt system requirements involving standardisation protocols, efficiency 'flows' and task-based care.

The resulting focus on what Saunders termed 'technique' may,[4] in turn, influence clinicians' understanding of palliative care as being 'just another specialty' concentrating on symptomology or as 'just another job' in medical care. Not all clinicians, however, will experience personal or professional discomfort in moving away from care that includes questions about total pain. Instead, they may choose to focus on developing new biomedical techniques shaping the frontiers of palliative medicine; or they may think total pain is an antiquated concept; or, perhaps, clinicians move between different understandings of the relevance of total pain and their ability to engage with it, depending on specific contexts.[6] The reality is that we currently have very little insight as to the relevance of total pain in clinical practice across the diverse range of settings and care populations that make up contemporary palliative care.

> “Is total pain best defined and understood as a care philosophy, a descriptor of personal experience, a relationship or a set of clinical practices? Is it even limited to end of life?”

Total pain: a continuing feature of palliative care

As a sign of the enduring importance of the concept of total pain, the majority of professional descriptors continue to use 'palliative care', 'total care' and 'holistic care' as synonyms, as evidenced in the current definition by the European Association for Palliative Care.[17] The concept of total pain has also significantly influenced EoLC advocacy and policy development, by being referenced either specifically or through associated terms. Clearly, total pain continues to be a foundational component in describing the benefits of contemporary palliative care. Yet collectively, the considerations outlined here may also indicate a troubling misalignment in terms of understanding the fundamental purpose of palliative care among diverse stakeholders. In turn, the substantial knowledge gap we have identified regarding contemporary definitions, clinical practices and relevance of total pain and total care may have serious consequences, both nationally and internationally, when designing future social and medical interventions for those nearing the end of life.

The need to address this knowledge gap is made even more pressing with ongoing sociocultural debates about what constitutes a 'good death'. With the increase in assisted dying legislation in the 'global North', initial studies indicate that non-physical suffering (constituting elements of total pain) is often the primary motivation behind requests for hastened death.[18] In the 'global South', questions arise regarding palliative care philosophies and practices that may not have the same cultural relevance as in the global North and, therefore, cannot be unproblematically transferred.[19]

> "With the increase in assisted dying legislation in the 'global North', initial studies indicate that non-physical suffering (constituting elements of total pain) is often the primary motivation behind requests for hastened death"

Future directions

Saunders advocated against a programmatic understanding of total pain and was most interested in the practical application of the concept. We sympathise with the reticence to 'operationalise' a definition, particularly in an era still defined by 'evidence-based' medicine. At the same time, given its continuing legacy in palliative care, we believe there is significant benefit in asking how total pain is understood and enacted in contemporary palliative care and EoL policy development. It is clear that a variety of stakeholders continue to rely on the concept of total pain, both explicitly and implicitly, to define the purpose and outcomes of palliative care. It is also clear that we currently have very little knowledge about contemporary understandings and relevance of total pain in these settings. To address this knowledge gap, the Glasgow End of Life Studies Group is currently engaging in a range of interdisciplinary, cross-cultural approaches to examine how the concept of total pain has been discussed and debated in palliative care and policy literature from 1964 (when Saunders first coined the term) to the present day. We are also exploring how palliative care specialists working in different clinical contexts in different parts of the world understand, assess and work to address total pain, and we will be mapping mainstream clinical interventions that specifically address total pain.

In the coming decades, global rates of dying will rise to unprecedented levels, and population ageing, cultural diversity and socioeconomic inequalities represent significant global considerations for the development of appropriate interventions to address health, well-being and social care at the end of life.[19,20] Palliative care is increasingly promoted as representing best practice across all populations and geographies.[21] As the specialty continues to expand and evolve around the world, advocates have even begun to champion access to palliative care as a basic human right.[22] Understanding how the foundational concept of total pain is understood and enacted in contemporary palliative care and EoL policy development is a pressing priority if palliative care is to be unreservedly championed at home and abroad ■

Key points

- Total pain refers to the intertwined physical, psychological, social and spiritual dimensions of pain.
- Addressing total pain requires both the prevention of physical pain and attending to patients' experiences of illness.
- The available research about total pain in clinical practice and policy is limited.
- Developing relevant end-of-life care interventions in clinical practice and policy requires in-depth knowledge of contemporary understandings of total pain.

Declaration of interest

The authors declare that there is no conflict of interest.

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Europe's first hospital palliative care team celebrates 40 years

Thelma Bates, Shaheen Khan, Andrew Hoy, Mary Baines and Barbara Saunders recount the story of Guy's and St Thomas' Palliative Care Team; how it grew from its humble beginnings and now celebrates its 40th anniversary.

Tall oaks from little acorns grow[1]

The original concept of the Guy's and St Thomas' Hospital Palliative Care Team was conceived in the fertile environment of St Christopher's Hospice in the 1970s. Dame Cicely Saunders had opened this hospice for terminally ill, mainly cancer, patients in July 1967. By October 1969 she had developed the first home care team and modern palliative medicine was born.[2]

In the early 1970s, one of us (TB), a consultant clinical oncologist at St Thomas' Hospital, London observed that the terminal care of one of her patients at St Christopher's was far superior to that which she was able to provide. Dr Mary Baines, a consultant at St Christopher's was eager to expand her knowledge and spent a week in the Oncology Department at St Thomas'. As a result, Dr Bates was invited to spend a whole day at St Christopher's reviewing all of the inpatients. Of these 54 patients, she identified five who she thought would benefit from palliative radiotherapy or chemotherapy or who would have benefitted if referred earlier. One, a frail patient with recurrent ascites, requiring very frequent tapping, probably due to an ovarian cancer was recommended a gentle sequential course of chemotherapy with chlorambucil and cyclophosphamide. The ascites stopped and the patient was able to return home for several months. Following this, Dr Bates became Visiting Oncologist to St Christopher's Hospice.[3–5]

It was during this period of mutual learning that it became clear that hospice skills were lacking at St Thomas'. Something needed to be done! The main obstacles were the negative attitude of many doctors to palliative, in contrast to curative, approaches to cancer and a lack of understanding of what could be achieved, particularly in relation to pain control.

Sister Saunders and Dr Bates on the ward, 1978

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[2] Freelance
[3] Princess Alice Hospice, Esher
[4] St Christophers' Hospice, London

The concept

The answer was to bring the hospice to the patient by providing a specialist hospice team to supplement the care of terminally ill cancer patients at St Thomas'. The plan was to start with a small team consisting of two specialist nurses and a specialist doctor backed up by Dr Bates and the hospital Chaplain in a voluntary capacity. The team would give advice and help at the invitation of the patient's consultant, but the patients would remain under the care of their own doctors and nurses, who they knew. Dame Cicely was encouraging. She offered to find the staff and spoke of a similar team at St Luke's Hospital in New York.

The St Luke's Hospital Hospice Team, New York

The team at St Luke's was the first hospital-based hospice team in the USA. It was founded and led by the Rev. Carleton Sweetser and began seeing patients in 1975. It worked in an advisory capacity without designated beds and termed their service 'scatterbeds'.[6] Dr Bates visited this team in 1976 when it was still in its early days and copied many of their ideas, for which she was grateful.

The planning

Introducing an advisory team into a large London teaching hospital risked implying criticism over existing care and also risked confusion over clinical responsibility. It therefore needed careful planning. Several months were spent finding out what consultants and ward sisters felt about existing standards of care. This was followed by discussions with the Dean of the Medical School, the Head of the Nightingale School of Nursing, and the Professor of General Practice to support the care of patients being discharged home. Armed with a clear operational policy, plus funding for the staff from the St Thomas' Special Trustees, the proposal passed through a committee stage, ending with official approval but with a reduction from the requested two nurses to just one nurse.

The St Thomas' Hospital Terminal Care Support Team[7,8]

The original team, called the Support Team, comprised Sister Barbara Saunders, an experienced nurse from St Christopher's, Dr Andrew Hoy, a doctor from St Christopher's who by now had decided to study oncology and was Dr Bates' registrar (and therefore acting in a voluntary capacity), and a part-time social worker, backed up by Dr Bates and the hospital chaplain, the Rev. Michael Stevens. In December 1977, the first patients were seen on four wards. Success on these wards resulted in some patients being able to go home, unblocking beds. This led to a rapid demand from other wards. Critical to this success were the skills of Dr Hoy and Sister Saunders who not only had the hospice skills but also had a sensitive understanding of the likely challenges of this new approach. A clear operational policy was important for the success of the team as it had to work in parallel with so many other services both in the hospital and in the community.

It was not always easy during these early days. Acceptance on the wards was not universal; one ward welcomed the support team doctor but not the nurse. At this time, it was not uncommon for consultants to tell a patient's relatives their diagnosis without informing the patient. This caused problems between patient and staff and conflicted with the palliative team policy.

During this first year the team worked in 26 different wards with patients referred by 29 different consultants and five general practitioners. By the third year, the team had four specialist nurses and was looking after up to 20 inpatients and 40 outpatients at a time (see Table 1). They were available 24 hours per day, seven days per week. During this year a full-time cancer research fellow with hospice skills joined the team, which allowed expansion of teaching and bereavement care.

Table 1. St Thomas' Hospital Support Team statistics for the first three years

	1978	1979	1980
New patients	207	236	234
Number of consultants referring patients	*29*	*37*	*46*
Number of GPs referring patients	*5*	*22*	*30*
Number of wards involved	*26*	*31*	*35*
Patients discharged home	93	139	117
Outpatients seen in the clinic	269	504	502
Home visits	301	1,339	1,435
Patients dying at home	24	46	49
Patients dying in hospital	105	139	116
Patients dying in a hospice	22	25	37
Bereavement visits	7	135	201
Teaching sessions	59	76	93
Visitors	44	109	115

■ Reprinted from The Lancet, 317, Bates, Clarke, Hoy & Laird, The St Thomas' Hospital Terminal Care Support Team: a new concept of hospice care, 1201–1203 ©(1981), with permission from Elsevier

As this was the first palliative care team in a hospital in Europe, there were many visitors and requests for advice, as well as invitations to lecture at home and abroad. The advice was always to plan in relation to local circumstances rather than copying the St Thomas' team per se. By 1987, there were 20 successful hospital palliative care teams in the UK.

In 1984, the Richard Dimbleby Day Care Centre was opened, providing a link between hospital and home for up to six patients three times per week, and in 1991 the first Sainsbury Professor of Palliative Medicine, Dr Geoff Hanks, was appointed. At this point Dr Bates handed over management.

The palliative care team today

Building on the leadership of the early pioneers, the palliative care service has expanded significantly. A clinical service is now

■ From left to right: Dr Shaheen Khan, Dr Andrew Hoy, Dr Mary Baines, Dr Thelma Bates, Barbara Saunders and Rachel Hill provided across both Guy's and St Thomas' hospitals and to the local community. The service also runs daily consultant outpatient clinics. Bereavement support includes an annual service for bereaved carers in Southwark Cathedral.

The service caters for patients who are faced with a life-limiting illness regardless of diagnosis and length of prognosis. It continues to function in an expert advisory capacity, working alongside colleagues of all disciplines to deliver support for patients and those important to them. This also includes peer support for fellow healthcare professionals. The palliative care team was recently awarded 'Team of the year' in the annual Trust awards, and has been selected as one of ten national vanguard sites for palliative and end-of-life care via the Building of the Best Programme.

Delivery of high quality symptom control, psychological support, advance care planning, and spiritual and social care are of key importance.[9] The service sees patients based on clinical need rather than prognosis. The palliative care team has worked with colleagues to lead a number of quality improvement projects across the Trust. This includes establishing end-of -life care (EoLC) as a board-level priority, developing a network of EoLC champions across the inpatient and community setting, plus initiatives such as the AMBER Care Bundle and the London Opioid Safety Improvement Group (LOSIG), supporting the roll-out of advance care planning via electronic palliative care coordination systems and working with colleagues in the community to support round -the-clock care for all patients in all locations. The service retains excellent links with local hospices, including St Christopher's and Royal Trinity Hospice, and has helped to lead the development of the Palliative Care Clinical Academic Group alongside the Cicely Saunders Institute of Palliative Care and the clinical team at King's College Hospital. Several members of the team lead on delivery of undergraduate and post-graduate multi-professional education. The service has an active programme of training, audit, research and guideline development, with a multi-disciplinary approach to all aspects of clinical and non-clinical work. This includes establishment of specialist social workers, matrons, clinical nurse specialists, consultants, training and non-training grade doctors and a specialist palliative pharmacist. Close working with colleagues from all disciplines is of key importance, including psychological support and chaplaincy services. The service is supported within the Trust directorate structure via links with the Head of Nursing, and is represented on the Trust EoLC committee that includes senior medical and nursing leadership.

> “The need for specialist palliative care services is increasing rapidly and the need to expand and demonstrate value is of paramount importance”

The future

The next 40 years will no doubt bring a new series of challenges as well as opportunities. The need for specialist palliative care services is increasing rapidly and the need to expand and demonstrate value is of paramount importance. The service is currently focusing on the routine use of data to improve the care that can be delivered, including integration of patient-reported and carer-reported outcome measures. Staff recruitment, retention and professional development are all priorities and all team members are supported with access to clinical supervision and postgraduate training. The team is leading the development of a Trust strategy for palliative and end-of-life care and is working with national partners to develop services across the UK. We hope the next 40 years can be just as successful and as significant for our team, our colleagues and the patients and carers that we have the privilege to serve ■

Declaration of interest

The authors declare that there is no conflict of interest.

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Key points

- **Historically, palliative care has grown along three paths; the hospice, the home care team and, more recently, the hospital palliative care team.**
- **The first hospital palliative care team in Europe was established at St Thomas' Hospital, London, in 1977.**
- **It worked by supplementing the existing care of terminally ill cancer patients without designated beds.**
- **Today, this team cares for patients according to need, regardless of diagnosis and length of prognosis. Specialist teams provide round-the-clock care in the hospital and local community for about 2,000 patients each year.**
- **There are now several hundred hospital palliative care teams in the UK, and they are becoming an integral part of the NHS.**

On healing and palliative care

Modern medicine has become so entrenched with the requirement for evidence, skills, competencies, outcomes and conformity that the concept of healing has been almost entirely forgotten. **Viv Lucas** investigates healing and what it means both as a concept generally and to palliative care specifically.

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The relief of suffering and the role of healing in its amelioration have become implicit within palliative care. They are, as George[1] says, our 'core business'. According to Mount and Kearney:[2]

> *'Healing is at the core of the palliative care mandate to support optimal quality of life when medical science can no longer modify the natural history of disease. While issues of healing and quality of life have a particular relevance in the setting of advanced and terminal illness, patients and their families want caregivers who are concerned with the healing of their illness, as well as the curing of their disease, throughout all stages of their disease trajectory and throughout all aspects of healthcare.'*

Yet when Kenneth Calman attended a Wellcome Witness seminar in 2012, he noted:

> *'... the word that hasn't been raised today, and I thought it might have been, is the word "healing", because a lot of what we do is about healing. And that's making wholeness, it's not necessarily curing. It's a phrase which I, because I'm getting older now, and I've*

Each night for nearly a thousand years (*c.*500 BC–*c.* AD 500), pilgrims visited the Temples of Asklepius – the Greek god of healing. They believed that the god would visit them during a dream state and either heal them or prescribe drugs, diet and modes of treatment via dreams that woud be interpreted by a priest. In return, the pilgrims would leave votives – stone or terracotta images of the body part that had been healed – to be hung on the temple walls. The ancient concept of healing has become lost in modern medicine. Illustration by Robert Thon, *c.*1952

FOTOFLIRT/ALAMY

> *read quite a lot about medical history and education, healing has been a central concept in medicine and that's what it's about. That means that you do something that makes people feel better.'*[3]

Healing is a concept that has all but disappeared from mainstream medicine.[4] George Canguilhem, in his essay 'Is a Pedagogy of Healing Possible?',[5] contends that, 'of all the objects specific to medical thought, healing is the one that doctors have considered the least.' The reason for this is that healing is, subjectively, what a patient is hoping for, but for a doctor, what is required is some sort of objective verification of the effectiveness of treatments. This relates to the way in which disease became objectified and the subjective patient experience effectively side-lined as biomedicine developed in the nineteenth and twentieth centuries. The emphasis was on treating the disease (the pathology, objectively verifiable) not the illness (the experience and concerns of the patient or diseased person).[6] This was the space into which Cicely Saunders entered and developed hospice care in the 1960s. Mainstream medicine had forgotten how to heal. What she brought to terminally ill cancer patients was a healing approach, 'rescuing' patients 'not only from inappropriate active tumor "cure" but also from inept terminal care'.[7] In her view:

> *'Healing a person does not always mean curing a disease. Sometimes healing means learning to care for others – finding new wholeness as a family – being reconciled. Or it can mean easing the pain of dying or allowing someone to die when the time comes. There is a difference between prolonging life and prolonging the act of dying until the patient lives a travesty of life.'*[7]

So if palliative care is about healing, and in Saunders' view its meaning is quite broad, it is curious that it was not mentioned in the seminar that Calman attended. He was Chief Medical Officer for England in 1995 and, with Deirdre Hine, wrote a report that effectively mainstreamed palliative care into cancer services.[8]

So why have we become so coy about healing? Is it because of the emphasis on evidence-based symptomatology, the assessment of skills and competencies, the demonstration of outcomes and the necessity to conform to external regulations in contemporary palliative care? Perhaps there is also the connotation from the lay use of the term 'healing' that it could imply such activities as the laying on of hands and should, therefore, be regarded with some suspicion.

Indeed, the word 'healing' began to get a bad name in the 1930s, the 'golden age' of scientific medicine[9] that lasted until the 1970s, and was then demoted to the 'domain of quackery'.[10] It was subsequently reclaimed largely by practitioners of alternative and complementary medicine (CAM). In spite of all the advances in orthodox medicine, there has, paradoxically, been a resurgence of CAM since the 1980s.[9,11] This may represent a search for healing no longer on offer within much of orthodox medicine. Palliative care services usually embrace and often promote complementary therapies as part of the holistic care that they offer.

Medicine derives from two traditions, the scientific, or Hippocratic, and the healing, or Asklepian. Broadly speaking, the Hippocratic model aims to treat disease, while the Asklepian cares for the patient. Cassell argues, 'There are not two goals. There is only one: the well-being of the patient.'[10] Kearney suggests that when we are trying to restore a sense of well-being in order to help those experiencing pain and suffering, these two traditions need to be integrated:

> *'Sadly, however, this is not what happens within contemporary healthcare, where Hippocratic medicine and Asklepian healing have become separated from each other in ways that do not easily allow for dialogue and co-operation. Whatever the reasons, Asklepian healing is lost in the shadow of Hippocratic medicine. This is both unhelpful and unhealthy and means that contemporary healthcare is cut off from ways of working that can bring healing to those who suffer.'*[12]

Palliative care integrates healing and science. It brings the two traditions together, allowing holistic care and facilitating healing.

What is healing?

Healing means 'to make whole'. It represents, 'a response shift in the person away from suffering towards an experience of wholeness that is not dependent on cure or the eradication of disease.'[12] Mount and Kearney describe it as, 'A relational process involving an experience of integration and wholeness, which may be facilitated by the therapeutic relationship and therapist's interventions, and which is dependent on an innate potential within the patient.'[2] In other words, suffering is diminished when healing takes place. In contrast to cure, healing comes from within; a process of inner change away from suffering. Healing is not about curing. It is possible to die healed. It is also possible to be cured but not healed.

So what is happening in this healing process? Cassell states, of healthcare generally, that:

> *'In their role as healers, physicians help reconnect sick persons to the world of the well, restore the competency of reason by providing explanations of events, provide alternative means and sources of control, and start patients on their way back to a sense of omnipotence. In all these acts, the doctor as healer helps provide a route by which the sick patient may regain the autonomy lost to sickness. The therapeutic instrument in healing is indisputably the doctor.'*[13]

■ **In contrast to the Asklepian tradition of healing, the art of medicine in the ancient world reached its zenith in Greece during the millennium between *c.*500 BC and *c.* AD 500. This creative period is symbolised by Hippocrates, the 'father of medicine', depicted here as he palpates a young patient sometime late in the fifth century BC. Illustration by Robert Thon, *c.*1952**

ROBERT THOM/ALAMY

Of course, it is not just physicians who are healers. In palliative care, all members of the multidisciplinary team contribute. In her book *With the End in Mind*, Kathryn Mannix[14] describes patients she has cared for in narratives that can be interpreted as stories of the healing process. This might be facilitated by the use of cognitive behaviour therapy to reduce the panic of breathlessness. For a woman with a pathological hip fracture, in despair that she might not be able to attend her daughter's wedding, it involved the technical fix of a hip replacement, the involvement of physiotherapists, nurses, a volunteer giving her a manicure, the hairdresser and the prescription of analgesics from the doctors. It also, importantly, involved interaction with another patient. This recovery from surgery took place in the healing environment of the hospice where the patient was enmeshed in a web of relationships bringing wholeness, helping her to achieve her goal. In this way, she was able to change her story from one of despair, to one of hope through a process of inner change. Healing is thus a facilitative process in which the patient emerges with a better story.

Cassell[10] has also broadly stated that, 'The basic aim of healers must be the enabling or return of function so that patients may pursue or achieve their purposes and goals.' This happened for the above patient who was able to attend her daughter's wedding. But clearly in the face of advanced, progressive illness such practical goals are not always possible, although there can be opportunities for healing until the point of death, for example, reconciliation within a family. Earlier referral to palliative care services, however, increases opportunities for healing. This is also reflected in the concept of rehabilitative day services as another aspect of healing. But the importance of day hospice patients who appear to be just sitting around talking should not be overlooked in favour of more active patients on treadmills and so on. We must be aware that patients form healing relationships with one another, as well as the staff, in a safe environment.

What is a healer?

Certain qualities are required to make an effective healer, whether doctor, nurse, complementary therapist, counsellor, physiotherapist or other discipline. Crucially, 'The healer engages in active listening (plain language, figurative speech, non-verbal communication) and asks, "Who is she?" (the sufferer); "Who am I?"; "What is the meaning of her illness – for her, for her family, for me?" '[15]

The concept and practice of 'active listening' is central to the therapeutic/healing relationship and is crucial in order to hear the patient's story, for 'suffering is personal, individual, and commonly expressed as a narrative.'[16] For in telling their stories, patients can begin to make sense of and find meaning in what has been happening to them. This is a fundamental part of the healing process. There is, rightly, a significant emphasis on 'communication skills' in palliative care and other healthcare disciplines. However, a healer needs to go beyond this and develop what Charon[17] calls their 'narrative competence', that is, 'the ability to acknowledge, absorb and act on the stories and plights of others.' Charon[18] argues that, 'until recently, doctors have paid little attention to their narrative training.' Yet listening to and interpreting the stories patients tell is a considerable part of a doctor's work. Hunter[19] has also emphasised the narrative nature of medical knowledge and practice; she suggests that the medical history is a 'text' which physicians interpret in much the same way as literary critics might examine a novel. As healers in palliative care, in whatever discipline, we need to really listen to the patient's story, which is different from 'taking a history'. And we listen with empathy,[20] using our imagination to try and understand the experience of our patient story teller; how it might be for them, not how it might be for us if we were in their shoes.

Conclusion

In palliative care we are healers because we generally treat illness rather than disease.

We are healers because we bring together the two traditions of medicine aiming to restore well-being to our patients. We are healers because we listen and facilitate. We try to help our patients make sense of their suffering by finding new meanings: 'In palliative care, we have learned to make no assumptions: we ask. The interesting thing is that people are able and willing to answer, and when they share that burden they often discover, from within themselves, new insights and ideas that help them cope.'[14] This is healing.

If we work in hospices, we have the help of a healing environment. If we see patients in their own homes or in hospital, our work centres around the formation of healing relationships, primarily with a patient, but secondarily also with their loved ones, who may also require some healing. If we explicitly embrace the concept of healing in palliative care, if we see ourselves as healers, we re-enforce the commitment we make to our patients and to the ethos of our practice ■

> "As healers in palliative care … we need to really listen to the patient's story, which is different from 'taking a history'. And we listen with empathy, using our imagination to try and understand … how it might be for them, not how it might be for us if we were in their shoes"

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Declaration
The author declares that there is no conflict of interest.

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Key points

- The role of healing in the amelioration of suffering lies at the heart of palliative care.
- Palliative care integrates the two traditions of medicine, the Asklepian (healing) and Hippocratic (scientific).
- Healing is a facilitative process from which the patient emerges with a better story.
- Certain qualities are required to be an effective healer, regardless of discipline, in particular 'active listening', helping patients to make sense of their suffering and find new meanings.

Using human-centred design in end-of-life care

■ The Helix Centre, a healthcare innovation lab within St Mary's Hospital in London, is tackling some of the most pressing problems within healthcare. Here **Ivor Williams** outlines some of the challenges and initiatives the Helix Centre has faced within end-of-life care; a field ideal for a human-centred approach.

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End-of-life (EoL) care is a specialty that covers all aspects of humanity, helping people at the end of their lives to live as well as possible until they die. Some people have a clear view of how they wish to be cared for at the end, many do not. Care and treatment at the end of life can be complicated, making an individual's wishes harder to deliver. While the UK leads the world in palliative clinical practice, with decades of pioneering research and a robust foundation of evidence, when it comes to adopting innovative practices and technology palliative care can often lag behind compared to other disciplines.

Human-centred design offers a powerful way to improve healthcare. By identifying individuals' needs and working with them, design can take a multifaceted approach to solving some of the most complex problems. Of all the areas in healthcare that would greatly benefit from design innovation and a human-centred approach, it is EoL care. Simply put, the needs are the most human: EoL care demands a holistic approach to support clinical treatments, along with emotional and social support for the patient and family, while always focusing on the relationships of everyone involved. We understand there is a desire from the global palliative medicine profession to set out and build a positive vision that tackles 21st century challenges, expressed with the flexibility to experiment, openness to collaborate and desire for change. Human-centred design is an effective tool to support the profession in its goals.

Applying design in healthcare at the Helix Centre

The Helix Centre is a healthcare innovation studio, embedded within St Mary's Hospital, and led by Professor the Lord Ara Darzi at Imperial College London. Established in 2014 as a collaboration between Imperial College and the Royal College of Art, we are a team of designers, technologists and clinicians tackling some of the most pressing challenges in healthcare.

We believe design and technology will play a natural and fundamental part in defining the next decades of EoL care. It is increasingly accepted that technology will continue to integrate into everybody's daily lives, and global healthcare systems as a whole are embracing technology at the heart of their work.

We employ various processes to rapidly dissect a problem, highlight areas of opportunity and prototype solutions. We collaborate internally alongside other subject matter experts to explore opportunity areas from their unique perspectives.

We consider everything from a user's motivations and behaviours, to the viability of potential business models, to the feasibility of technological execution. We co-create solutions with frontline healthcare professionals, academics and the general public.

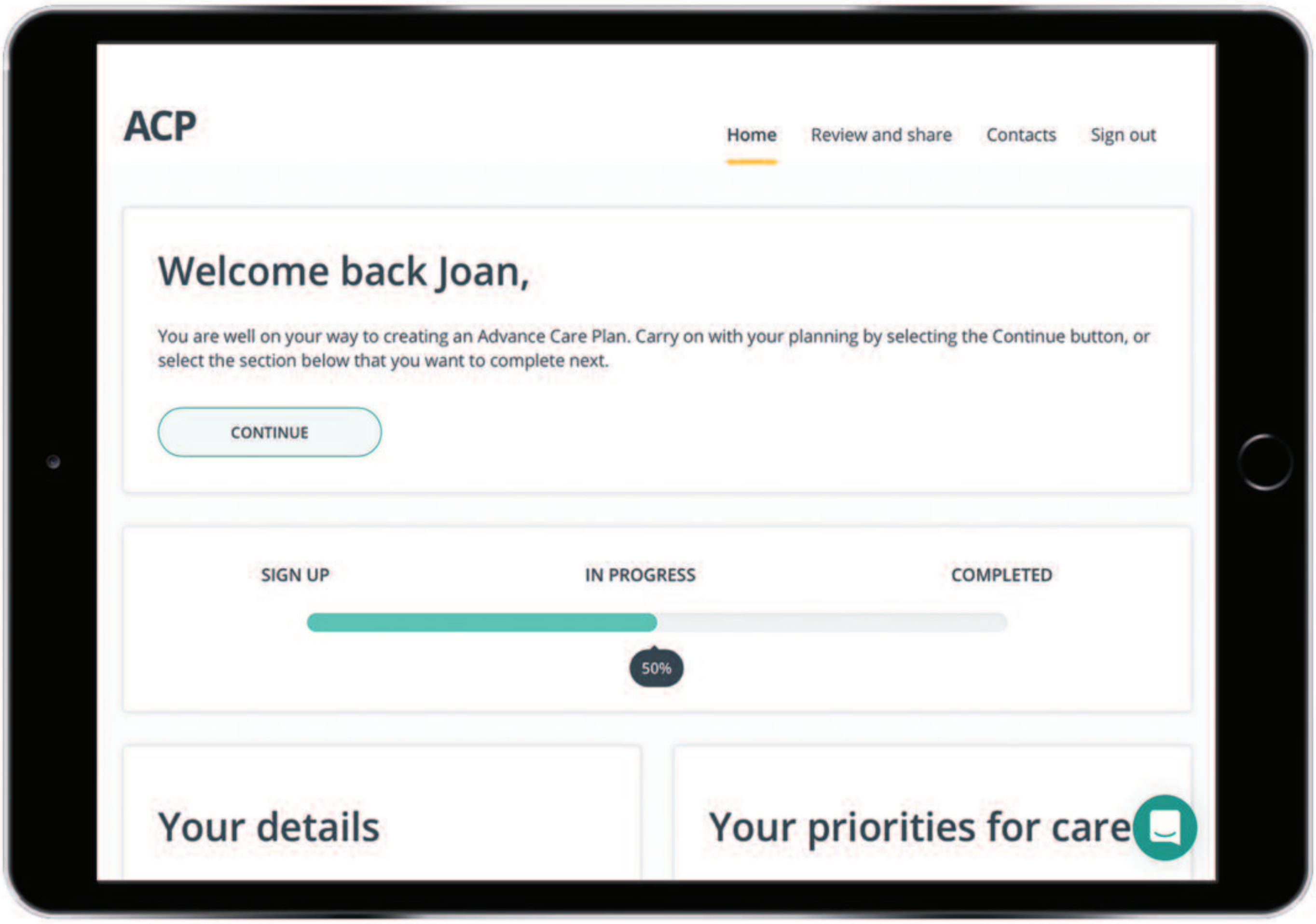
We have a dedicated team who work on a number of EoL care projects. Our aim is to research and design innovative solutions that improve the quality of life for those – young and old – living with life-limiting conditions or who are at the end of their lives. We are committed to alleviating suffering for dying people, empowering them to live their lives to the fullest and to transform the support and experience their families and carers receive, as well as professionals and health systems alike. We have been developing three active areas of work that broadly address EoL care in the hospital, the home and in the hospice.

Enabling conversations in emergency care settings

To understand the current problems for EoL care, we must begin in the place where death occurs most: hospital. Nearly half of all deaths in England occur in hospitals (223,007 out of 469,975 in 2014[1]), with 69–82% of those needing palliative care.[2] Despite the high numbers, only 3% actually want to die in hospital.[3]

Talking about death in a hospital can be incredibly difficult. The curative setting builds the expectation for patients that they are going to get better, and will receive long-prolonging treatment at all costs. Many feel that the responsibility for discussion around palliative or EoL treatments should come from clinicians.

EoL care in this context is often delivered last minute, following an acute episode. This places



Welcome back Joan,

You are well on your way to creating an Advance Care Plan. Carry on with your planning by selecting the Continue button, or select the section below that you want to complete next.

Your details

Your priorities for care

extraordinary strain on patients, families and clinicians to have meaningful conversations in a short time frame, about the possibility of dying. These conversations at the EoL often centre around decisions not to resuscitate the patient.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms are used to make specific clinical decisions for an individual if their heart or lungs stop working. Their use is widespread in the NHS and was put in place for 94% of patients' notes at the time of death.[4] DNACPR forms have been linked to many problems, however. The forms vary within NHS Trusts and community settings, meaning that some people have multiple forms to suit each setting, and there are cases of DNACPR forms having been created without the knowledge of the person or their loved ones. Having difficult conversations about declining health is a vitally important part of how we care for people with life-threatening conditions.

To help improve the way in which EoL care is delivered – and in collaboration with the Resuscitation Council and a working group of 30 national organisations – we have helped redesign the way in which difficult conversations about life-sustaining treatments are conducted and recorded with a new form and process called ReSPECT. ReSPECT is a clinician-led process that brings the patient to the centre of emergency care decisions.

> "Talking about death in a hospital can be incredibly difficult. The curative setting builds the expectation for patients that they are going to get better, and will receive long-prolonging treatment at all costs"

At the heart of the ReSPECT process is a form designed to guide a conversation between healthcare professionals and patient. It features a visual device used to demonstrate that there is often a compromise between sustaining life and providing comfort and dignity. We helped to clarify this process for patients, to make it accessible and easy to understand.

One of the biggest challenges in introducing a new procedure to the healthcare sector is educating and supporting the people that need to use it. Indeed, clinicians get very little training in holding 'difficult conversations', specifically and EoL care in general. So, in response, Helix created a prototype web app to provide accessible training and support for clinicians using the ReSPECT process. This prototype was then further developed and delivered to professional audiences in a collaboration between Helix Centre Clinical Research Fellow Dr Gehan Soosaipillai, UCLPartners and Tom Stables Associates. This new digital tool enables healthcare professionals to learn about the new process with interactive training scenarios and discussion tips.

The new ReSPECT process is to be trialed in over 130 sites across the UK and Ireland, and is currently being evaluated by Warwick University.

Making advance care planning more personal and better connected

As the population ages, and medical knowledge advances, the importance of giving people more choice and control over their care has never been greater. Getting people to fill in an advance care plan (ACP) has been shown to be highly effective in aligning healthcare with patients' wishes, reducing hospital bed days in over-65s, and moving deaths from the hospital to the community.

However, filling in ACPs is human-resource intensive and putting a strain on GPs, palliative care teams, charities and volunteers. As a result, not enough plans are being completed. We understand that carefully structured conversations that explore patients' values, not forms, will be the key to increasing uptake of ACPs. While they are predominantly person-to-person or form-based, these services can struggle to scale.

We have successfully created the first spin-out venture from the Helix Centre, called Digital Care Planning. With NHS funding, it is modernising the way in which ACPs are created and shared within the network surrounding a person living with a life-limiting disease. It does this by genuinely focusing on their individual needs and priorities for care using technology. We learned that some people prefer to establish their priorities of care quickly, whereas others wish to take their time and discuss the details. Surprisingly, we learned that although technology skills vary from person to person, the acceptance of new technologies – voice technology, chatbots – was higher than originally anticipated. Our approach allows everyone to define their plan according to their own preferences, promoting autonomy and independence, and moving at a pace that is most comfortable.

> “... filling in ACPs is human resource intensive and putting a strain on GPs, palliative care teams, charities and volunteers. The result is that not enough plans are being completed”

Our platform, Amber Care Plans is an easy-to-use, free website that captures people's future care decisions through an accessible user interface designed for real people, not healthcare professionals. You can learn about all the various aspects of an ACP, record your decisions easily, print off for your personal records and digitally share with loved ones. As one Marie Curie volunteer remarked, 'I'm thinking about my family when filling this out. It's great to know they have something to guide them.'

As well as creating a truly person-centred advance-care planning tool, we are scaling the ability to create and capture digital care records for the UK health service. Our goal is to connect people with the right healthcare professionals, so that when the time comes, everyone knows what that person wants and needs. The website – amberplans.com – is live, with plans in place to integrate with NHS services in the near future.

Developing the future of hospice care

Medical innovations of the 20th century radically changed the ways we died, moving us from the home to the hospital. In this new century, we need to build a better relationship with death. One that is open and inclusive, allowing us to understand and create better networks, services and places in order to help us to live well until we die.

It is our mission to define and help deliver future forms of EoL care, using contemporary and emerging technologies and practices, and we're looking at how we can do that in the hospice sector. Hospices perform the most specialised and experienced EoL care in the UK, caring for around 360,000 people each year.[5] They are excellent places to meet the many needs of the dying person. However, they suffer from a variety of problems, not least of all the fact there are too few referrals from community services and hospitals to hospices, which means that patients lose out on the experience of hospice staff near the end of their lives.

Given many people do not access specialised hospice care, informal carers play a significant role. In any future care model, the needs of these caregivers must be considered; the caring burden is physical, mental, emotional and financial, causing high levels of anxiety and stress over a long period of time.

The experience of dying is a deeply human one. It is a uniquely emotional, psychological, spiritual – even mystical – time that everyone will go through. Death can be a terrifying prospect, but good EoL care can make a huge difference. We believe that to make radical improvements to

Key points

- The Helix Centre uses human-centred design to rapidly dissect problems, identify opportunities, and develop clinically evaluated digital solutions.
- End-of-life care demands a holistic approach that is perfectly suited to human-centred design.
- ReSPECT is a new process that puts the patient at the centre of emergency care decisions. It is intended to replace DNACPR.
- Amber Care Plans have been designed to modernise the way advance care plans are created and shared.

the holistic care of the dying person, there is a greater need to support their psychosocial – spiritual, emotional and psychological – needs. It is vital to not only serve those needs, but to broaden the abilities of those caring for them, both professionals and non-professionals.

With the amount of care being delivered by informal – often family – carers, it is vitally important that we train people to become carers, and then support them in being the best carer possible. This can be achieved in the long term through education, or by identifying unmet psychosocial care needs and better enabling and equipping people today, to deliver that high level of care.

We have identified five pressing issues in hospice care, describing the desire for self-administration of pain relief, the notion of social death, coping with compassion fatigue, accomodation of illness and loss, and death anxiety. These issues were factored against six methods to tackle these problems such as peer-to-peer support, training and skills management, new and emerging therapy practices, self-management and others. We are currently developing three new prototype services that tackle some of these complex issues, leveraging the expertise of the hospice movement and the desire for radical change. Patients and families are seeking new tools to support long-term complex needs, to be empowered to care for each other – in their family and in their communities. If done appropriately, technology has a powerful role in enabling this.

By combining human-centred design, relationship-based care models, evaluating and implementing existing and emerging technologies with evidence-based research, we believe we can transform the experience for patients, their loved ones and professionals. We think design can make a huge difference in improving clinical and social outcomes and to the effectiveness of EoL care services, particularly for hospices. We are working to establish a tangible vision for the future of EoL care, that supports everyone to live as well as possible – with all the joy, sorrow and meaning that comes with it – until the very end ■

Declaration of interest

Ivor Williams is a co-founder of Digital Care Planning, the start-up behind Amber Care Plans.

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Book review

P.S. I have cancer: wrestling melanoma and falling in love

Sims, M; Bristol: Poetry Space Ltd, 2018; 308 pages; PB (RRP: £9.95; ISBN: 9781909404274)

***P.S. I Have Cancer* is the raw and incredibly human account of the life of Dr Mark Sims, a junior doctor with stage 4 melanoma. Mark's story begins at his diagnosis, days before his 27th birthday, and ends with a chapter written by his mum, Sue Sims, giving life to the future he'd never have. It closes with a final letter written by Mark's fiancé, Georgie, for his memorial service. What could be a tragic read is not. Instead of being floored by this prognosis, Mark drew light from dark, using his story to affirm who he is and what he loves: science, Europe, Center Parcs, family, friends and Georgie – and also to air his bugbears: Brexit, alternative medicine, and, indeed, the spelling of Center Parcs. The result is a bridge between memoir and a love letter to, well, everything.**

Mark frames his story in a science lesson as well as an ode to science. He strikes a delicate balance: accessible for the masses without patronising the scientists. As well as dissecting each step of his trajectory to diagnosis and treatment – no evidence or symptom is disregarded – Mark exercises his prerogative to heal through educating the reader about melanoma. And so many other things, really: explanation always follows unfamiliar lexis.

Mark's gratitude for medicine and how it enabled him to wrestle melanoma is emphasised, not least through his ongoing plea for donations to Cancer Research UK. Indeed, this commitment to research – to the extent that Mark agrees to donate his body to science – lessens the futility of his death and allows him to actively retain his doctor's identity, never succumbing to that of 'cancer patient'. There is something of a mentor/protégé relationship between Mark and his oncology consultant, characterised by implicit awe, unwavering trust and respect.

Mark writes with a palpable urgency; he has a lot to say and knows there is little time in which to say it. His literary sincerity also reflects the speed of his mind: every tangential thought necessitates digression. No detail is neglected and an intimacy begins, almost as though we're privy to Mark's stream of consciousness: before long you feel quite connected to him.

Pleasantly contrasting with this directness are the poetry, prose and roses that adorn the love story between Mark and Georgie. As with all good romances, it began with a tight dress and a Vodka Revs dance floor and, like a lovestruck teen, Mark recalls and records every detail of their time together, giving their love the longevity it warrants. Indeed, Mark was surrounded by love and argues that this love supercharged his immune system.

Mark's relationship with life is a joy. In the perverse way that only the terminally ill manage, Mark successfully subverts his disrupted timeline and extracts wonder from the mundane. A day spent feeling fit enough to go for a bike ride and a coffee becomes nothing short of heavenly. A trip to Center Parcs replaces a South African safari. Rather than stressing the injustice of life and this cruel twist of fate, Mark chooses to see its beauty and somehow manages to rebrand Center Parcs as a microcosm of the best of Europe within a few square miles. Words like 'inspiring' and 'brave' become glib and hollow through overuse, yet it is clear that Mark was sincerely all of these things, and it is a privilege to get to know him through these pages. It is hard not to feel cheated by Mark's fate, yet his story uplifts and affirms. None of us have tomorrow and we would do well to remember that ■

Emma Matthews, Staff Nurse, Weston Park Hospital, formerly of the Royal Marsden Hospital, London

The plight of palliative care in Kenya

■ **Sayed K Ali's** touching account of daily palliative practice in Kenya highlights the current state of the field in sub-Saharan Africa and the need for further and continual change; both in attitude and service provision.

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She was 64-years-old, but looked markedly older. The metastatic cancer had ravaged her body. She lay in her bed, curled, motionless, covered by a soft pink blanket. Her 'comfy blanket', she called it, now old and mangled, had been with her since childhood and seemed to somewhat ease her pain. Her nephew, perhaps in his early twenties, ushered me into her room. The curtains hindered any sunlight making it difficult to see at first. A fan on the wall lay static, the blades full of reddish dust. The smell of dettol antiseptic was overpowering.

'Mrs Botham, this is Dr Ali', I attempted to say, but she lay motionless. 'I am here to see you', I added, but no response. I knelt down and tapped her shoulder, she moaned; her eye barely open, lips chapped, with irregular sores. I gently tugged on her pink blanket. She held it strong, but not for too long; her strength gave up, she let go. Her pillow, equally mangled, had strands of gray hair on it. The multiple rounds of chemotherapy had certainly taken a toll, but the cancer was unrelenting. Her protruding cheek bones and sunken eye in the dim light gave her a ghastly look. A plate of cold rice pilaf accompanied by a glass of water lay by her bedside. It didn't look appetising and I wondered how long it had been sitting there. It was obvious she hadn't eaten in days.

'How is your pain doing?', I managed to say.

'Horrible', she moaned. 'My back hurts', she whispered.

'May I listen to your chest', I added. She nodded reluctantly.

I pulled my stethoscope and placed it on her bony chest. Her breaths were shallow, effortless. Her heart was beating fast, faster than I could count. Turning her was cumbersome, but as I palpated her spine, I could clearly feel the cancer pulsating beneath my fingertips. I wanted to squash it. I wanted her to beat this. We both knew this wasn't possible. Certainly, she was approaching death.

She had been getting her sublingual morphine frequently, but this seemed to help only a bit. I made a mental note to increase her morphine, perhaps switch it to a different opioid if the family could afford it. Administration of a different opioid might be challenging. Maybe a fentanyl patch, I thought, or a touch of steroid for a few days.

In the West, where I trained and where opioids are plentiful, I would not have to ponder this much. However, I was in Kenya and this made it challenging both medically, financially and socially.

My thoughts were interrupted by her nephew. 'Is she going to die?', he whispered. He caught me off guard and I knew that Mrs Botham had heard this. I politely gestured an exit. Once outside Mrs Botham's room, I mentioned she probably had a few days to live, but it was hard to give an exact number. Perhaps this boy was too young to understand the complexity of the issue. Standing under the light bulb, he looked tired, dark circles engulfing his eyes. He nodded in agreement, perhaps appreciation, I could not clearly tell.

'We should let some sunlight into her room', I managed to say. 'I think it will do her some good and help orient her to time of day'. He nodded, taking mental notes. 'Some ice-cream, maybe her favourite flavour, would be good for her', I added. He nodded again.

'I will let my family know', he said as he led me to the front door. 'Thank you for coming. We really appreciate all your help'.

I handed the nephew a few prescriptions and discussed with him what to monitor for. I asked him to call me if he had any questions or concerns. I promised to come back in a few days to check on Mrs Botham. We shook hands.

Out of the house, I welcomed the refreshing warm rays of sunlight shining directly on my face. How much we take for granted, I sighed. I promised myself to appreciate every healthy day. I had made similar promises in the past, but quickly forgotten them. As I drove back to the clinic to tend to my afternoon patients, I could not help think how we could improve the quality of life for people with terminal illnesses in Kenya.

A few days later as I was finishing some notes, I got a call from Mrs Botham's nephew. He was sobbing on the phone and alerted me to Mrs Botham's death the previous night. 'She went away peacefully', he said. Even though expected, I still felt my heart sink. I gathered myself and shared my condolence, offering to help the family in any way possible. We ended the conversations acknowledging each other's support in taking care of Mrs Botham. I hung up the phone, but my mind was already racing to think if I could have done anything differently to help Mrs Botham and her family.

Palliative care is still in its infancy in Africa and even though strides have been made, many gaps still remain in providing care to patients with terminal illnesses. Cancer in addition to other chronic diseases, seems to have caught up to HIV-related deaths. Unfortunately, there are few palliative care physicians in Kenya, too few to manage the number of growing cases. The concept of an inpatient palliative care unit is still emerging and much work needs to be done. Often financial burdens, lack of access to significant grants, as well as structural limitations are seen as the major challenges in setting up a palliative care service or unit.

Physician attitude to dying and chronic illnesses needs to change as well, allowing palliative care services to be involved in patient care earlier on during the trajectory of their chronic illness. A rigid curriculum to teach palliative care to upcoming training doctors and other medical professionals is direly needed. Home visits remain unpopular and are limited by the distances and traffic, especially in and around Nairobi. In addition, cultural norms, tribal influences and traditions often pose a significant challenge to end-of-life conversations and care.

Most palliative care teams encompass a variety of providers to deal with the different dimensions of chronic illnesses and death, including but not limited to pain, spiritual and psycho-social. To have an effective team that fully addresses the needs of patients while dying, adequately trained nurses, a psychologist, spiritual counsellors, social workers and physician are crucial, but lacking. Training and education often takes time and resources, and can be difficult to justify to health care managers.

Having said this, I have seen a small change; a shift to accept palliative care as an important service not only for patients and their families, but physicians as well. Some families reach out to the palliative care providers to help when all else fails. These providers are always happy to provide care, even late in the disease process. This change is most notable within the academic faculty and the medical residents. Perhaps this small change is the spark needed to accomplish big strides.

> “To have an effective team that fully addresses the needs of patients while dying, adequately trained nurses, a psychologist, spiritual counsellors, social workers and physician are crucial”

Mrs Botham's tale is one of many that has shed light on the dire need for palliative care in sub Saharan Africa. She might be one of the lucky ones, since many are not able to afford medications or expert care at a major hospital or at home. They have to rely on untrained family members, often children, who the majority of the time are overwhelmed dealing with fatigue, fear of the unknown and caregiver burn out.

Some nights I often wonder if patients like Mrs Botham would have been better cared for if they had been admitted to an inpatient palliative care unit. I believe the development of a functional palliative care team and eventually a unit remains an attainable vision in Kenya. A unit that can fully address end-of-life symptoms both medically and psycho-socially; both for the patients as well as their family members.

Mrs Botham's funeral was attended by many family members and friends. They were all dressed in white wishing Mrs Botham safe travels as she moved to the future realm. I stood at the back, inconspicuously paying my respects as her body lay on a mound made of dry wood. She looked peaceful, surrounded by flowers of all kinds. She wished to be cremated and her ashes sprinkled in the Indian Ocean. A slight breeze seemed to flame the fire, unexpectedly, but hurriedly attempting to release the trapped, almost impatient soul from the once ravaged, but now lifeless body. Finally she was free. No more in pain. Part of me felt content for her, happy for her liberation. 'Safe travels, Mrs. Botham', I whispered, as I quietly left to tend to my afternoon clinic ■

Declaration of interest
The author declares that there is no conflict of interest.

Key points

- Palliative care is in its infancy in Africa and despite much progress, gaps remain in the provision of care to patients with terminal illnesses.
- Access to, and provision of, opioids in Kenya is far more challenging than in many Western countries, with medical, financial and social barriers to be overcome.
- There are few palliative care physicians in Kenya, too few to manage the growing numbers of cases.
- Physician attitude to dying and chronic illnesses needs to change as well, allowing palliative care services to be involved in patient care earlier on during the trajectory of their chronic illness.


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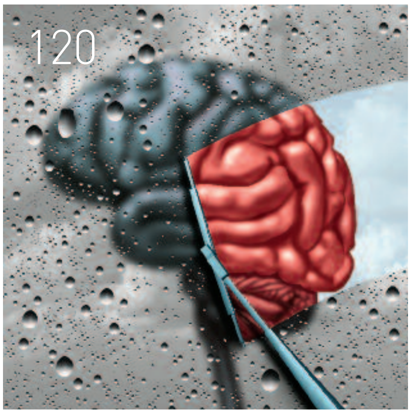
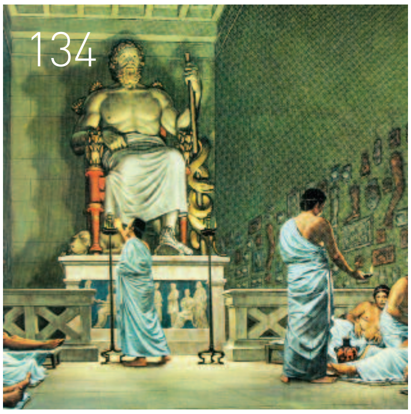
Highlights in this issue

Contents





TOP TO BOTTOM
ASPHOTOWED/iSTOCK
LIGHTSPRING/SHUTTERSTOCK.COM
FOTOFLIRT/ALAMY