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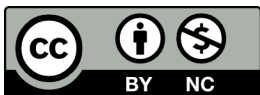
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ORIGINAL ARTICLE

Standardising care of the dying: An ethnographic analysis of the Liverpool Care Pathway in England and the Netherlands

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Abstract

The Liverpool Care Pathway for the Dying Patient (LCP) was a prominent set of guidance in the late 2000s and early 2010s within palliative and end-of-life care. Developed in England to improve the care of dying patients, it was later adopted in 20 counties. After a public scandal, it was removed from practice in England but remains in other locations, including the Netherlands. Drawing on two sets of ethnographic data, from England and the Netherlands, we consider the ways in which the LCP was engaged with as a form of standardisation aimed at improving practice, how it was deployed in relation to other forms of knowledge, and the political and moral statements that are being made through the (selective) use of it. Looking into the use of the LCP shows that, while the LCP attempts to standardise some of the values associated with palliative care, there are significant differences between how these standardised values are then enacted in different institutional and national contexts and by different individual care professionals. We conclude that the LCP was used to impart moral values, establish protocols of care, and demonstrate professionalism, showing the multiplicity of the use of standards in healthcare practice.

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KEYWORDS

death, end of life care, guidance, palliative care, standards

INTRODUCTION

Within hospice and palliative care, the saying by Cicely Saunders (recognised founder of the modern hospice movement) that ‘how someone dies lives on in the memory of others’ is used to justify the need to focus on how people are cared for at the end of life. Palliative care provided within hospices is considered to provide an idealised form of end-of-life care (Economist Intelligence Unit, 2015; Lawton, 2000), which is person-centred, holistic and enables a ‘good death’ (McNamara et al., 1994). An attempt to recreate hospice-style care in other settings is exemplified in the Liverpool Care Pathway (LCP or fully known as The Liverpool Care Pathway for the Dying Patient). The LCP was designed in the 1990s in England and rolled-out nationally over 15 years and subsequently in other countries, including the Netherlands where it was first implemented in 2003 (Veerbeek et al., 2008). The LCP is an example of medical guidance designed to standardise care practices to improve the quality, efficacy, and reliability of clinical practice.

Clinical guidelines are developed by decontextualising the evidence embodied within them (Knaapen, 2014), and draw on an assumption that their use will have similar outcomes in different settings. Research to date has examined the ways in which clinical standards and guidance are created; however, as Moreira suggests, we need to research guideline careers ‘through implementation and use examining how it is affected and affects health care contexts’ (2005:1984). Whilst there have been many editorials and several articles describing the career trajectory of the LCP, including critiques of its evidence base and wide-scale implementation (MacKintosh, 2015; Prentice & Amer, 2016; Watts, 2013), we follow Timmermans and Epstein’s recommendation that standards need to be studied empirically in terms of how they are used (Timmermans & Epstein, 2010). Our research here then seeks to do something different than most of existing literature about the LCP, which has sought to add to the evidence base for or against the standardised guidance. Rather, by using ethnographic data from different care settings in two countries, namely England and the Netherlands, we explore how the LCP was implemented and used in practice, detailing the varied ways in which care professionals engaged (or not) with attempts to standardise the care of the dying in particular ways. Seymour and Clark have produced several articles that examine how the LCP was created and implemented (Clark et al., 2020; Seymour & Clark, 2018); adding to their analyses we present data on how the LCP was encountered, utilised, and at times was an ambivalent tool in everyday care practices in different contexts. This enables us to provide a nuanced understanding about how such guidance shape and are shaped by end-of-life care.

Since the LCP was developed with the intention to standardise end-of-life care, we first turn our attention to a short history and description of the LCP. We then review literature about medical guidance and standards to understand how such objects come into being, their relationship to knowledge and practice, and how they are implemented. Subsequently, we outline the methods we used to study the LCP, both in our individual ethnographic studies and how we used these different datasets collaboratively to inform the analysis presented here. Next, we turn to an analysis of the ideals behind the LCP, its implementation and use in practice as observed in our respective ethnographic studies.

BACKGROUND TO THE LIVERPOOL CARE PATHWAY

The Liverpool Care Pathway was designed under the direction of John Ellershaw in the late 1990s in Royal Liverpool University Hospital. It was to be a tool to transfer what was considered good end-of-life care from hospices to hospital settings, initially for patients with cancer but later adopted for general use (Sykes, 2015). Initial reviews of the LCP indicated that nurses found it beneficial, and it had a positive effect for patients and their families (Jack et al., 2003). Based on the principles of the design and initial findings, the Department of Health for England and Wales recommended the use of the LCP beyond Liverpool. From 2004, the National Institute of Clinical Excellence, which sets the guidelines for evidence-based medicine in England, endorsed the use of the LCP in palliative care (Pugh et al., 2010). Soon the LCP was referred to as an example of 'best practice' in policy documents, most notably in the national End of Life Care Strategy in 2008 (Department of Health, 2008), and supported through financial incentivisation in England.

Yet, in 2013, following a public scandal and review in England, the LCP was recommended to be removed from clinical practice. The Daily Mail (a middle-market tabloid newspaper in the UK) ran a series of articles which challenged the use of the Liverpool Care Pathway. These highlighted family stories about not knowing that someone was dying, highlighted that hospitals were paid to use the documentation, and featured doctors who publicly discredited it. The 'scraping of the LCP' in England was claimed as a victory by the newspaper. The review, led by Baroness Neurberger, found that when well implemented and supported by education and processes, the LCP could 'work well', but that this was too inconsistent, operated like a 'tick box exercise' and that many families felt the use of the LCP hastened the death of those they loved (Neuberger et al., 2013, p. 3). Such drastic reactions to the LCP and subsequent policy changes have not been witnessed in other countries that adopted the tool.

Internationally and nationally, the spread of the LCP has been supported through personal connections enabling it to be championed and adopted (Clark et al., 2020). In the Netherlands, the LCP was initially implemented through an intervention study from 2003 to 2006 in two hospitals, two nursing homes, and two home care organizations (Veerbeek et al., 2008). Subsequently, the LCP was further distributed through palliative care networks, ErasmusMC and the Dutch Cancer Centre (IKNL). Besides changes in layout, one major difference in the Dutch version was that goals regarding the continuation of clinically assisted nutrition and hydration have been placed under the heading 'evaluation of actions and discontinuation of unnecessary treatment' (Swart et al., 2003). While the Dutch translation was presented as three different versions, one for hospitals, nursing homes, and home care, the only difference between them was the use of the terms patient, client, or resident, to refer to the dying person. By 2008, 25 institutes were working with the LCP (Veerbeek et al., 2008). There is an assumption here that the common goal of 'quality of care' is understood in the same way in dissimilar contexts, and that the same steps are required or even possible to achieve it.

The LCP is a multipage document to be used by care professionals and kept in the patient's records to support, but not replace, clinical judgement. It has gone through multiple versions, with the latest being Version 12; Version 4 was used to create the Dutch translation, entitled *Zorgpad Stervensfase* (Swart et al., 2003). Several sections of the document outline what it is to be used for and how to use it, by promoting regular reviewing the patient and multidisciplinary teamwork, and include information that could be given to a patient's relatives. Section 1 is organised around nine domains—communication, facilities, spirituality, medication, current interventions, nutrition, hydration, skin care, and explanation of the plan of care—which each have one or more 'goals' listed within them. Section 2 provides a checklist for the assessment of symptoms

and is supposed to be filled out every four hours. In both sections, the goals are stated with a tick box option of 'achieved' or 'variance'. Variance, as the guidance notes suggest, does not mean failure on the part of the team but acknowledges that this is a process and the contextual nature of care. Clinical teams are encouraged to note why variances have occurred and action plans to correct them—a whole page is dedicated to this and in practice this was to support team learning and continuous improvement. The final section outlines goals related to care after death, such as verification and notification of death.

UNDERSTANDING MEDICAL GUIDELINES AND STANDARDS

Systematically developed, guidelines are designed to provide statements about the course of action for specific clinical circumstances (Field & Lohr, 1990). They are one of the main tools used by clinicians and policy makers to reduce variability in care, and increase efficiency, reliability and quality of care (Gawande, 2011; Moreira, 2005). The importance of guidelines in clinical practice illuminates the ways in which the Liverpool Care Pathway embodied the authority of clinical guidance and how this has been accepted or rejected as the knowledge of 'best practice'.

Although often portrayed as monolithic, medical knowledge is socially constructed and multiple whereby social relations as well as technical knowledge and belief affect what becomes medical facts or medical knowledge (Mol, 2003; Young, 1987). Western biomedicine formulates what it knows—particularly how the body and disease are viewed—in a 'culturally distinctive fashion' with a focus on the body (Good, 1994, p. 65). An extensive industry of medical science generates new knowledge about health and medicine through the application of scientific standards, while, at the same time, there has been a rise in viewing the patient as an expert with particular insight into their body and how to manage their illness (Mol, 2008).

The development of clinical guidance seeks to transform this varied knowledge into standardised, actionable information to guide practice. In doing so, knowledge—often rarefied further as 'evidence'—is collated and appraised through value judgements (Knaapen, 2013; Moreira, 2005). Whilst this process generates a decontextualised consensus of idealised standard practice, producing and promoting guidance seeks to embed the evidence within a wider framework of how care should be delivered. However, clinical guidance is made through assessment not only of the evidence and its validity based on scientific standards, but also of its social acceptability (Moreira, 2005). In this way, clinical guidance is not just statements of standards or 'best practice', as it is often portrayed, but also political and moral statements about medical practice in the current context of when it is devised.

Moreira (2012) identifies three main models in which social science analyses of standards are made sense of. Firstly, the domestication model shows how actors adopt and adapt standards to their own practices. We will show this, particularly in the context of the Netherlands with translation, but also how limited this adaptation has been. Similar to other studies, we discuss how staff continued to use their own discretion and other forms of knowledge as well, indicating nuanced ways in which standards are engaged with (Björnsdóttir, 2014). The socio-technical model describes how standards and contexts are in a continuous and emerging interactive relationship; and this describes some of the early development of the LCP with 12 versions being generated. Lastly, the catalysing model shows how the deployment of standards is responsible for generating or accelerating the formation of new, local, differentiated singularities; this has not been evident in our data but could explain what has occurred in England since the removal of the LCP.

In all of these analyses, it is evident that standards do not remain abstract ideas or items, but are things that are engaged with, partially employed, resisted and remade and in doing so, can shape and are shaped by the (care) practices which they become part of. This is important because some of the critiques made about the LCP have questioned the evidence base for the creation of the guidance, particularly the lack of trial data (Sleeman & Collis, 2013). When the LCP was being developed, integrated care pathways and quality improvement projects were popular within healthcare systems and these influenced the ways in which the LCP was designed and implemented (Seymour & Clark, 2018). The rise and fall of the LCP in England reveals much about the political and moral sentiments about end-of-life care during that time (see Neuberger et al., 2013). It is therefore important to consider the ways in which the LCP was engaged with as a form of guidance that could standardise, with the intention of improving practice, and how it was deployed in relation to other forms of knowledge and the political and moral statements that are being made through the (selective) use of it. In taking this position, we seek to present a nuanced interpretation of standards in healthcare practice rather than assume such documents only encapsulate objective scientific evidence or political values.

Seymour and Clark analyse the process through which the LCP was implemented and scaled up in the UK, how it then became subject to public debate and how it was eventually discontinued (Seymour & Clark, 2018); they have also analysed the spread of the LCP into 20 countries (Clark et al., 2020). In seeking a theoretical explanation for this national and international spread, they use the concept of 'boundary objects,' which they define as 'an artefact that provides a means of sharing ideas, technologies and practices across and between organizational settings, cultures and communities' (Seymour & Clark, 2018, p. 4). They reason that the LCP initially functioned as a 'positive' boundary object, meaning it succeeded in bridging differences between its stakeholders. As its use was scaled up, however, the tool was increasingly dependent on knowledge brokers and gradually became a 'negative' boundary object, meaning that, rather than bringing diverse perspectives and experiences together, it exposed discrepancies between groups and generated conflict. On an international scale, their research has demonstrated that much of the diffusion of the tool outside of the UK relied on personal networks and individuals willing to champion and implement the tool in other contexts (Clark et al., 2020). In their analysis therefore, it is evident that even though the LCP operated as a form of clinical standard, it still relied on individuals to make it effective.

STUDYING THE LCP ETHNOGRAPHICALLY AND COLLABORATIVELY

The genesis of this article came from a chance meeting at the annual conference of the American Anthropological Association in 2016. We discussed our ethnographic fieldwork about end-of-life care, our encounters with the LCP and began talking about similarities and differences in its use, how it was removed in the UK but not in the Netherlands, and what it meant for standards like the LCP to travel across geographical boundaries, care settings, and be used in the care of the dying. For this article, we set out to collaboratively analyse and write about our ethnographic data drawing on our own previous, independent fieldwork. We have addressed the ethical issues of conducting our ethnographies in other publications (Borgstrom, 2014; Lemos Dekker, 2020; Lemos Dekker et al., 2018).

We have set out in this article to think about the LCP as an ethnographic object—something that is used in particular settings in ways that we can describe through observation and

ethnographic analysis. It tells us not only how the document is used as a tool in care provision, but what it means for those using the tool and how using the tool is part of wider values and practices around caring for dying patients. We are therefore recognising how documents, like the LCP, are examples of artefacts of modern knowledge worthy of ethnographic response (Riles, 2006). Ethnographic observations of how documents are used have demonstrated that people can ignore or alter checklists and tick boxes to suit their own agendas (Reed, 2006). Rather than focus on the details of the document then, our analysis focuses on the ways in which people broadly engaged with the LCP or aspects of it, and the questions that this then enables us to ask about end-of-life care more broadly.

Ethnographic projects and context

Erica's research has focussed on end-of-life care in England, with a specific focus on the discourse in end-of-life care policy, and how people are cared for towards the end of life (Borgstrom, 2014). This has included observations in hospitals, hospices, personal homes, and care homes as well as interviews with doctors and nurses, both within palliative care and in other specialisms or with generalist healthcare providers. She interviewed policymakers focussing on end-of-life care, and people facing end-of-life care issues either as a patient or caregiver. A key element to her work has been exploring core concepts utilised in English end-of-life care, such as choice and advance care planning, and the practices that support or challenge these discourses, including the LCP.

Natashe has studied the social processes and management of death and dying with dementia in nursing homes in the Netherlands. Central to her research have been the moral frames that become apparent in discourses and experiences of the end of life with dementia. Her ethnographic study, set in two nursing homes, included interviews with people with dementia, their family members, and professional caregivers. The LCP was approached as one of the possible ways through which the end of life was managed in nursing homes. Professional caregivers' experiences of working with the LCP were addressed and its use in practice was observed (Lemos Dekker et al., 2018).

Collaborative ethnographic analysis

Collaborative analysis of multi-sited ethnographic work, like in this paper, is relatively rare (Miller et al., 2016, pp. 36–37; see for example Collier & Broom, 2020). We have sought to collaboratively analyse our data about the LCP from different projects to understand how the guidance was encountered and used in daily practice. Our overall process is informed by interpretative analysis, noting that 'comparison' here does not mean a direct like-for-like comparison due to the different contexts that were under study.

Initially we shared thoughts about our projects and jointly asked questions about how the LCP was designed, 'travelled' and the values around creating, politically adopting, and using the LCP. We then individually consulted our datasets more closely to select excerpts that related to the LCP to share and analyse. These were put in separate documents that enabled us to asynchronously add our reflections on our own and each other's extracts, identifying potential themes. These were then discussed during several calls where we began to highlight similarities and differences across and within the datasets. This process was re-iterated to refine the themes and identify salient extracts.

By placing the data together as we have here, we have also deliberately looked at ‘deviant cases’—where our data did not easily compare or left us with additional questions for each other—to further understand how the LCP was encountered in our fieldwork. This enabled us to illuminate and challenge cultural assumptions about clinical guidance and end-of-life care practices in our different contexts. Importantly, we did not assume that differences in our datasets were determined because of differing national and cultural contexts; others have demonstrated that national differences do not necessarily cause differences in knowledge practices and politics within a range of issues within medicine and healthcare (Akrich et al., 2015).

Overall, our process is similar to a meta-ethnographic approach by drawing on different ethnographic studies to understand a particular topic (Noblit & Hare, 1988). However, it differs since we drew on our own research, enabling us to contextualise our findings via our ethnographic experiences. By bringing together our studies we created a new analysis of our work using a common analytic frame around clinical guidance, focussing on the ideas behind the tool, how it was implemented, and how the document was used in practice. We have focussed on what the data can tell us, acknowledging that the original data collection had other purposes and intentions.

IDEALS BEHIND THE TOOL

While clinical guidelines represent what is considered ‘best practice’, they may, in so doing, also capture political and moral statements about medical practice. Specifically, within end-of-life care, the LCP is such an example. The purpose of designing the LCP was to take what was viewed as routine and best practice within hospices and transfer this to other care settings, particularly hospitals and nursing homes. Hospices are commonly associated with the aims of enabling people to die in less-medicalised surroundings and to improve their quality of life. The term hospice care is often interchanged with palliative care, defined by the WHO as ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (WHO, 2002). In taking hospice care for the dying as a best practice, the LCP was designed to shape the dying process aligning with a palliative care view of what a ‘good death’ is (Watts, 2013). It thus also subscribes to the political and moral framework associated with palliative care, particularly its historical philosophy that suffering towards death is to be minimised not only through the use of medications, but by also attending to other elements of care, and a suggestion that biomedical ways of treating a person are inappropriate for this.

Pathways are considered to function both as management and educational tools to improve the quality of care (Bookbinder et al., 2005)—providing guidance on what should be done and when as well as providing a document trail of what has been done. In the Dutch case, the LCP was considered to stimulate multidisciplinary collaborations by structuring and documenting end-of-life care. Moreover, under the umbrella of ‘quality of care’, it was implemented from the conviction that professional caregivers lacked knowledge to observe symptoms and to mark the dying phase (Veerbeek et al., 2008). As one nursing home physician told Natashe, he thought professional caregivers needed to improve their ability to recognise the end of life and that the LCP would support them in doing so.

Yet improving quality of care was not the only motivation to implement the LCP. The LCP was also seen as a way to make palliative care ideals tangible and visible within the various care

institutions. Natashe noted that the use of the LCP was mainly promoted by the nursing home geriatrician, who saw it not only as a way to structure care, but also as a means to communicate professionalism to family members of the residents. As the geriatrician put it, with the LCP ‘you approach the end of life in a very professional way. The family can see how their relative is being observed and which actions are taken, so they don’t have to worry about this.’ The LCP was thus thought to make the provided care more visible (Lemos Dekker et al., 2018). In the care institutions where we did our fieldwork, we thus found that while care institutions search for ways to implement palliative care ideals and aim to make these ideals tangible and visible through tools such as the LCP, these ‘best practices’ are not only aimed at improving care but may also be implemented to demonstrate that care is provided in a professional manner.

ROLLING OUT THE STANDARD

While the LCP was designed to transfer palliative care values between care settings in a standardised manner, one of the themes that both of us came across during our ethnographic research were discussions and actions around how this standard was to be rolled out in these various settings, across national and institutional divides. This included how the LCP featured as a recommended ‘best practice’ tool in policy documents, end-of-life care programme newsletters, and events in the UK (Borgstrom, 2014), and how the LCP was promoted by institutions and palliative care networks in the Netherlands (Lemos Dekker et al., 2018; Veerbeek et al., 2008). Whilst such macro and meso-level interventions are important to understand its relative prominence in each country (see Clark et al., 2020 for similar), we focus in this section on some of the micro practices that sought to embed the LCP as part of standard practice within our respective field sites.

During Erica’s fieldwork, one of the common discussion points between her and the palliative care team staff that she worked with was their role as facilitators in LCP education for other staff. Many of them ascribed to the notion, which was promoted in national end-of-life care policy at the time, that ‘end-of-life care is everyone’s business’ (Department of Health, 2008) and that palliative care staff, who have more regular exposure to dying, could play a pivotal role in teaching others about this in order to spread ‘best practice’. This meant that in some instances they championed tools like the LCP in their local clinical settings. For example, in one hospital that Erica visited, two palliative care nurses planned a hospital-wide drop-in session about the LCP to coincide with a national dying awareness week. This session provided space to ‘show people how to use the tool’ (which by this point had already been implemented in the hospital for several years but had variable usage) and ‘reassure others’ that they could use it without specialist palliative care knowledge. The nurses also held an ‘information table’ in the public canteen area of the hospital one lunch time to hand out information sheets and promote the usage of the LCP amongst hospital staff (the table with bright posters and smiling nurses was visible to patients and visitors as well). In the hospitals where Erica did her fieldwork, despite the LCP being ‘rolled out’ with educational sessions in the past, the teams were frequently receiving ‘referrals to palliative care’ with the ‘sole purpose of completing LCP’ documentation or advising on how to action it, ‘even though training had been offered’ as one consultant said. When questioned about why they offered such education (both formal and informal), the consultants and nurses typically expressed a desire to ‘improve the quality of care’ at the end of life and viewed the LCP—and supporting other staff with the LCP—as a means of doing this.

Similarly, in the community settings that Erica visited, staff trained in palliative and end-of-life care found themselves in educator positions about the LCP. Sometimes this was a formal role, but other times this was something they had volunteered for after seeing how low or inconsistent LCP uptake was in the area. For example, one district nurse who used to be a palliative care nurse took it upon herself to encourage others to use the documentation — but ‘in reality, a lot of it is extra work that I do because I care about it’. Flicking through a folder of paperwork, she lamented that uptake by others was often ‘poor’ and that her focus was on encouraging care homes to start using it more by identifying that someone was dying. She hoped that the LCP would give them the confidence to provide ‘the right kind of care’ at the end of life and avoid sending everyone who is ‘normally dying’ into the hospital. ‘The LCP tells them what to do’ was how she saw it and meant that the care home ‘was not alone’. Ultimately, she viewed the presence of the LCP document in care homes as an extension—or insertion—of palliative care into those spaces, especially at times when staff like herself or her specialist colleagues were not present or on call.

In Natashe’s fieldwork, it became apparent that education in the use of the LCP was not standardised practice. Only a few care workers indicated that they had received any training in using the LCP, while others said they had not. The implementation of the LCP in the various care units, then, was quite heavily dependent on the presence of care staff who knew how and when to work with the tool. They would often explain aspects of it to their colleagues while the LCP was being used, creating a form of informal learning. Not having standard training for new employees could create a knowledge gap, when a care worker who had been familiar with the LCP left the nursing home. This shows how some care workers had a pivotal role in the roll-out of the LCP in the various units. Expertise regarding the LCP in this setting was thus particularly tied to the individual care workers rather than to the care institution.

In the small care units of the nursing home, which consisted of up to eight residents, there could be extensive periods of time between deaths. It was quite common for six months up to a year to pass without any of the residents dying. For the nursing staff in these units, this meant that they would only use the LCP with large intervals. Some nurses indicated that they had to familiarise themselves anew with the tool, each time an LCP trajectory was started, in order to be able to use it. ‘When it has been a while since I’ve worked with it,’ one care worker said, ‘I really need to get the hang of it again. How did it work again, and what was it that I had to do?’ This need to reacquaint themselves with the LCP, however, was not only due to the irregularity of its use but was also attributed to the complexity of the document itself (Klapwijk et al., 2020; Lemos Dekker et al., 2018). Apparently, for nursing staff, the document did not speak for itself and required substantial background knowledge, habituation of use, and education, in order for it to be rolled-out smoothly in the workflow of the staff.

In their analysis of the LCP, Seymour and Clark note how the LCP as a boundary object relies on knowledge brokers to ensure that it is translated from one setting to another. In other reviews of the LCP, particularly in commenting on why it was removed from practice in the UK, it has been noted that education around the LCP was variable and that this impacted the (proper) use of the documentation. As our examples illustrate, there were many reasons why education around the tool was likely to be variable, but it also came with a lot of individual passion and dedication to support staff across care settings to understand what the LCP was and how it could be used. This often reflected a belief by those promoting it that its use had the potential to improve the quality of end-of-life care that people were receiving, and relatedly, the experience of dying. The LCP therefore did not just represent a set of standard procedures to be followed but was thought to embody and enable particular values around death and dying, and an idealised version of care of the dying.

USING THE DOCUMENT IN PRACTICE

Having shared several examples of how the implementation and education of the LCP was discussed in our field sites, we now turn to examine several ways in which our interlocutors used the documentation or commented on the use of the documentation by others. Looking into the use of the LCP in practice shows that, while the tool does function to standardise some of the values associated with palliative care, there are significant differences between the ways in which these are enacted in different institutional and national contexts and by different individual care professionals.

In a hospital-wide meeting that Erica attended, the comments about the LCP at the time (prior to 2013) suggested that the staff thought it was ‘generally good’ and something they used. What made it good was that it ‘prompted certain aspects of care that might otherwise get neglected, such as mouth care’. Similarly, care workers in Natashe’s fieldwork were generally positive about the way the LCP structured symptom observation. ‘It offers a kind of guideline,’ one care worker mentioned. ‘Did I check everything and look at all symptoms? Did I indeed look at the medication? Did I discuss everything?’ Especially the checklist of symptoms provided in the document was valued as a ‘reminder’ of all the things to consider when a resident was dying. Care staff particularly valued the LCP as a tool that pointed ‘all noses in the same direction.’ In other words, they felt that starting an LCP raised awareness among all care professionals involved that a particular resident was dying and fostered a common understanding of what types of care and intervention were deemed appropriate. The LCP, staff members told Natashe, ‘helps to create continuity within and between all disciplines. So that we are all on the same page.’ It created a sense of clarity that a resident was in the palliative phase and that sometimes-difficult decisions to withhold treatment and focus on comfort were legitimate. Without the LCP, staff members explained, colleagues could hold different opinions and approaches as to what care to offer. Yet, having introduced the LCP, it provided a framework through which such decisions could be evaluated, legitimised, and agreed upon. ‘At that moment, your colleague can also say, all right, we are now in that phase.’ Starting an LCP, then, was also considered an important marker of consciously, and actively, starting the ‘palliative phase’ of a resident, and aligning the associated values behind the provided care.

Considering this, the LCP was also used as a means of communication towards family members: to not only align the expectations and approaches of professional caregivers at the end of life, but also those of family members (Lemos Dekker et al., 2018; Veerbeek et al., 2008). As one care worker told Natashe, ‘The LCP has started, and that usually is a sign for family members that it is not going well. That [the resident] is truly in her final stages of life. This can be quite abrupt, so usually I try to prepare family members for this, when I see it coming, by saying that the geriatrician may soon want to start the LCP.’ However, in this use, ‘starting’ the LCP may create the impression that there is a choice as to whether to ‘start’ dying or not—whereas, of course, the LCP is aimed at assisting caregiving in the dying phase and used as a marker of the onset of the dying phase (Klapwijk et al., 2020; Lemos Dekker et al., 2018; Veerbeek et al., 2008). The language of ‘pathway’ in this sense, has negative connotations in relation to death both in English and in Dutch. In the UK, part of the critique on the LCP has been precisely on the term pathway and the idea of ‘putting someone on the pathway’, where a key recommendation was to stop referring to such documentation and care practices as ‘pathways’. Regardless of its terminology, Natashe also saw that, while for some professional caregivers communication with and to the family was crucial to the LCP, there were substantial differences between the different care units. Some kept the document in the staff office rather than in the resident’s room, and some

staff members actively sought involvement of relatives where others did not. Many professional caregivers did not discuss the LCP with family members, and family members were in many cases not even aware of its use. Several care workers even questioned the added value of discussing the LCP with the family: 'I wonder if [knowing about the LCP] actually matters to the family. I think it is more important to show that the care for the dying resident is as optimal as possible. And knowing what kinds of tools we use for that, that is of no use to them.'

Overall, the experiences of using the LCP were quite ambivalent. As part of shadowing palliative care staff in a regional hospital in England during 2011, Erica noted that one of the main reasons the staff were called onto wards to see patients was 'because of the LCP'—often junior staff on wards were tasked with filling it out and wanted to check they had done it correctly. At other times, the lead consultant joked that for some wards, the palliative care team proactively would go to see if the ward had 'done it right themselves'. Apparently, this was mixed, with certain wards being 'consistently worse' and often they 'did not fill out many of the boxes'. The LCP was not being used as intended, and so the palliative care team took it upon themselves to check use and encourage 'better use' through liaising in patient notes, providing informal training and encouraging attendance at formal training. Erica came across similar sentiments several years later in other hospitals with discussions about how much the form would be used by others given that not even all palliative care staff routinely used it. Even though the LCP had been around for years and was supposedly 'integrated into care' it 'didn't have much uptake' or when it was used, certain sections were consistently 'left out, such as the spiritual section' as one nurse noted.

The document was also experienced as burdensome: being too complicated and too much paperwork. In the Dutch nursing home context, the LCP was used in addition to regular care records, which meant that filling it out caused double work. Particularly the basic information to be documented in the first pages of the LCP was considered superfluous and would already have been documented in the resident's care files. Considering that residents lived for a longer period of time in the nursing home, care staff, physicians, and managers were already familiar with them and their families. It also turned out to be unclear how the LCP was to be aligned with the regular care record. Some care staff told Natashe that they thought the care record would be closed the moment a LCP was started, and that the care provided would only be recorded in the LCP, whereas others indicated that they continued reporting in the regular record, and filled out the LCP additionally. Generally, care staff expressed to Natashe that they considered the LCP to be poorly adapted to the nursing home context. Even in the English hospital setting, where it was portrayed to Erica as if the palliative care team were fully behind the LCP and were intent on seeing it utilised as it had been designed, individual staff members pointed out that the form was 'already too long' even before patient notes were factored in and that it 'had too much writing'. They were concerned that colleagues who 'already don't read it or fill it in' would further disengage with it. 'Staff already struggle to find the time to write in patient notes [maintaining paper and electronic copies at the time], why would they fill in a form now as well?' was how one consultant framed it.

Perhaps on a more fundamental level, both authors' interlocutors questioned, if often implicitly, to what extent the values incorporated in the LCP were leading in, or made a significant difference to, the provided care. To a large extent, care professionals drew from their own experience and values in providing care at the end of life. One of the consultants that Erica interviewed, for example, suggested that when it came to end-of-life care, it was a time when you could see clinicians 'not acting in their 'scientific evidence' manner, as they have beliefs about life and death, and intent and cause-effect, that can be difficult to separate out'. This consultant suggested

that this influenced how and when the LCP documentation was used by different staff members, which may not even be a bias they recognised in themselves or in others. She felt that what happened then in the context of dying—and whether the LCP was used—was an example of how ‘care was not being delivered based on what was clinically right but on people trying to be right’. Further, when it came to the actual care provided, care staff, and especially more experienced care workers, told Natashe that they thought the LCP did not make a fundamental difference. They indicated that the care they would provide when using the LCP in fact did not differ much from the ‘regular’ care for the dying they would provide without the LCP. They stressed the importance of knowing their residents well, knowing their preferences and their family members, in order to provide good care at the end of life. They found it easier to recognise symptoms in the residents they knew well, with the LCP being of secondary importance. ‘End-of-life care is our core business’ said one geriatrician, indicating that palliative care values were well integrated in the care for the dying in the nursing home setting, regardless of the LCP—‘In practice you do the same, only now everything is compiled for you in a list.’

CONCLUSION

By examining data about how the Liverpool Care Pathway was used in different contexts in two countries—England and the Netherlands—we have been able to articulate a nuanced analysis of how the tool was used. As stated by Sleeman and Collis, ‘the hospice movement has shown us that it is possible to provide good care to people who are dying. The failure of the LCP has demonstrated that translating this care to other settings is far from straightforward’ (Sleeman & Collis, 2013, p. 1). The two main institutes that collaborated in the implementation process and continue to promote the LCP in the Netherlands—IKNL and ErasmusMC—stated that ‘we do not recognise the serious criticism of the LCP in England in the Dutch practice’ (Lemos Dekker et al., 2018). Our analysis provides some insights into the variability with which it has been used across different settings. By doing so, our analysis crucially illustrates that guidance tools are only functional if people are involved. This resonates with other research on evidence-based tools for standardising practice that illustrates that such tools are not ‘neutral’ (Overton, 2020), and that standards require human expertise to work (Hogle, 1995; Timmermans, 2015). Therefore, understanding how people make sense of and use these is imperative.

The LCP was designed to help standardise the care of dying people. As a document, the form was intended to be a source of knowledge to guide practice, helping practitioners see dying and the dying patient anew. However, as other research has demonstrated, actual use can differ from intended use of standards (Timmermans & Epstein, 2010). Indeed, through our ethnographic data we illustrated various examples in which the document needed interpreting—required education, training, and knowledge brokers to ensure it could be used as intended. Moreover, some staff (such as the care home workers in the Netherlands) found that it did not necessarily improve what they knew and wanted to use it at their own discretion and alongside other forms of knowledge. So rather than being able to uniformly standardise care through standardising knowledge and practices, the LCP became one of many ways in which professionals made sense of and enacted patient care.

Overall, we have used two ethnographic datasets to understand the use of the Liverpool Care Pathway in two national contexts and different professional groups. We acknowledge that this means our data is not directly comparable, and appreciate that some of the differences we observed (e.g. around motivations to use the tool) can be explained by how different professional

groups align themselves with the LCP and their idealised versions for its use as part of their care provision. For example, the palliative care staff Erica spoke with wanted to educate others and saw the LCP as a tool for education and care, whereas for the nursing home staff that Natashe engaged with, used the LCP to strategically demonstrate professionalism in their interactions with families.

In this paper, we have focussed on the LCP as an ethnographic object. Doing so enabled us to move away from thinking of the LCP as an example of how documents aim (and/or fail) to standardise practice or as boundary objects that generate agreement across diverse practices. We demonstrated how the LCP was intended to standardise moral values and practice around end-of-life care, both nationally and internationally. The LCP was enacted as a material practice to be followed (as a tool) and a textual checklist, which at times had limited transformative power, even if also aligned with training on how to use the tool. In some cases, it was not used to transform care but to make existing care visible and demonstrate professionalism, which confirms others' insights about standards in care (see Knaapen, 2014 for a summary). In this way, the LCP was not only being used to enact values specific to end-of-life care focussed on the quality of dying, but general healthcare values of professionalism, accountability and transparency. The LCP therefore simultaneously has multiple uses including imparting moral values, standardising practices, and demonstrating professionalism. This multiplicity overlaps, without an explicit hierarchy and can create tension in practice, both for those using it and those impacted by its use.

Unlike other theorists, users, and commentators who discuss standards in healthcare practice, especially those discussing the Liverpool Care Pathway, we do not view standards as either solely scientific documents with clear benefits, or as purely political value-based documents that spread ideological thinking. Rather, by examining the implementation and use of the LCP in practice, we have sought to illustrate the subtle, and at times troubled, ways in which the LCP sought and achieved to standardise values associated with palliative care. Importantly, however, our analyses reveal significant differences between the ways in which these standardised values are then enacted in different institutional and national contexts and by different individual care professionals. Rather than presenting a straightforward narrative that valorises or demonises the Liverpool Care Pathway, collaborative ethnographic analysis enabled a nuanced appreciation of how the implementation of Liverpool Care Pathway attempted to improve the quality of care for dying patients and a variety of subsequent responses to using the tool in practice.

AUTHOR CONTRIBUTIONS

Erica Borgstrom: Conceptualization (Equal); Data curation (Equal); Formal analysis (Equal); Funding acquisition (Equal); Investigation (Equal); Methodology (Equal); Project administration (Equal); Resources (Equal); Writing – original draft (Equal); Writing – review & editing (Equal).

Natashe Lemos Dekker: Conceptualization (Equal); Data curation (Equal); Formal analysis (Equal); Funding acquisition (Equal); Investigation (Equal); Methodology (Equal); Project administration (Equal); Writing – original draft (Equal); Writing – review & editing (Equal).

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DATA AVAILABILITY STATEMENT

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available. Where data is derived from policy documents, these are publicly available.

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