Professional caregivers’ experiences with the Liverpool Care Pathway in dementia: an ethnographic study in a Dutch nursing home

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Abstract

Objectives: There are few observations of how professional caregivers apply the Liverpool Care Pathway (LCP) in nursing home care for people with dementia. Further, despite critiques in the UK, the LCP continues to be used in the Netherlands and to our knowledge no studies have been conducted since its implementation. The purpose of this study is to analyse professional caregivers’ experiences with the LCP in this context.

Methods: The article draws on an ethnographic study. Data collection was based on four months of ethnographic fieldwork in 2015 in 11 psychogeriatric units of a nursing home in a rural area in the Netherlands. Data collection included participant observation and 25 semi-structured, audio-recorded interviews with specialist elderly care physicians, nursing staff, and a nurse practitioner.

Results: In the experiences of professional caregivers we saw that the LCP was appreciated as a communication tool and as a reminder of care goals. However, the document was deemed too complicated and caused a duplication of work. It was observed that the LCP did not cover the complexity of care needs that emerge in practice. Actual care needs were prioritized over the LCP, which calls its contribution into question.

Significance of results: Overall, the LCP does not match the context of dementia care in the nursing home. While it could be argued that the LCP does not intend to replace good care, its benefits as a reminder and a communication tool need continuous consideration in relation to the amount of work it requires as a bureaucratic obligation.

Key words:

Liverpool Care Pathway, dementia, nursing home, professional caregivers, ethnography

Introduction

People with dementia in the last phase of life often suffer from burdensome symptoms such as pain and shortness of breath (van der Steen, 2010; Hendriks et al., 2015). They may not verbalize complaints, or express these differently, and recognizing such symptoms may be even more difficult in acute illness or in the dying phase (Robinson et al., 2014; Davies et al., 2015; Waterman et al., 2016). Anticipating and identifying symptoms is important for timely symptom management. Pathways and observational tools such as the Liverpool Care Pathway (LCP) may help to monitor symptom burden and to guide care at the end of life (Jack et al., 2003; Veerbeek et al., 2008; Mayland et al., 2013). However, there is very little evidence of the effectiveness of end of life pathways to relieve symptoms (Brännström et al., 2016; Chan et al., 2016). Further, when mistaken for a protocol it may also divert the caregiver's attention away from a person-centred approach (Neuberger et al., 2013; Sleeman and Collis, 2013; Venkatasalu et al., 2015).

In the UK, the LCP has received substantial criticism and has been phased out from July 2014 (Neuberger et al., 2013). In different countries among which the Netherlands, the LCP is still being used (Veerbeek et al., 2008; Clark et al., 2012; Di Leo et al., 2015). In the Netherlands, the LCP was initially implemented through an intervention study that took place between 2003 and 2006 and included two hospitals, two nursing homes, and two home care organizations (Veerbeek et al., 2008). Subsequently, the LCP has been further disseminated through palliative care networks and the Dutch Cancer Centre IKNL. By 2012, 119 institutes including 35 nursing homes were working with the LCP (Geijteman et al. 2013). The Dutch translation, *Zorgpad Stervensfase*, was based on version four of the LCP (Swart et al., 2003). In the UK separate goals have been formulated for the continuation of clinically assisted nutrition and hydration, while in the Dutch version, these goals were included under the evaluation of actions and discontinuation of unnecessary treatment. Other goals were retained in the translation (Swart et al., 2003). There are three Dutch versions of the LCP, for hospitals, home care, and nursing homes that differ only in the use of the terms 'patient', 'client', or 'resident', respectively to refer to the dying person.

In response to the critiques of the Neuberger report regarding the use of the LCP in the UK, the two main institutes that collaborated in the implementation process and continue to promote the LCP, namely IKNL and the Erasmus Medical Centre in Rotterdam have issued a statement, declaring that "we do not recognize the serious criticism of the LCP in England in the Dutch practice" (Erasmus MC and IKNL). This argument is substantiated by referring to an initial implantation study of the LCP in the Netherlands that evaluated its effects as predominantly positive (Veerbeek et al., 2008). However, this has been the only study on the LCP in the Netherlands, and to our knowledge no additional research was conducted in the Netherlands after criticisms were published in the UK. As such, while IKNL and Erasmus MC remain convinced of its benefits, there has been a considerable gap in our knowledge on the ways in which the LCP has been functioning and how it has been experienced by caregivers and family members. Furthermore, to our knowledge there are also no studies that have addressed the LCP specifically in dementia care.

In this study we ask: *How do professional caregivers in a Dutch nursing home experience working with the LCP in the context of dementia*? Considering that one of the aims of the LCP is to support caregivers in providing care at the end of life, we are interested in evaluating to what extent they indeed consider the LCP as supportive. As such we address the usefulness of the LCP in the specific context of nursing home care at the end of life with dementia. Our ethnographic approach enabled us to address both professional caregivers' experiences and to follow the use of the LCP in practice. In examining the challenges and benefits of the LCP in the daily practice of long term care, we address how the LCP relates to the particularities of dementia.

Methods

Design

The ethnographic study was conducted in dementia care units in a Dutch nursing home between March and June 2015. This work was part of a larger ethnographic study on what constitutes good care at the end of life. NLD used participant observation and four cases of LCP use were closely followed. NLD conducted 25 semi-structured interviews with professional caregivers that were guided by the topics experiences, challenges and benefits of working with LCP in the context of dementia in a nursing home setting. Interviews lasted between 25 and 60 minutes.

Setting and participants

In the Netherlands, LCP use has not been mandated. The nursing home selected for this study was situated in a rural, southern area of the Netherlands and staff had been working with the LCP since 2005. There were 11 psychogeriatric small-scale living units, each with eight residents, almost all with dementia.

To account for different understandings and experiences of working with the LCP, interviews were held with all 4 specialist elderly care physicians, the nurse practitioner and 20 nursing staff.

Transcripts and analysis

The interviews were focused on discussing how the LCP was perceived by professional caregivers and allowed them to reflect upon it, while participant observation allowed NLD to collect data on the actual use of the LCP in practice. The interviews were recorded, transcribed verbatim and coded by NLD (medical anthropologist). A sample of the transcripts was analysed independently by MG (medical anthropologist) and JvdS (epidemiologist) with open coding. Observations were recorded in detail in field notes by NLD on the same day. These descriptions were then shared with the other two researchers, who read them and came together for joint discussion. Throughout data collection and analysis, the insights from the observations were compared with the findings from the interviews and discrepancies were discussed. Employing a grounded theory (Glaser and Strauss, 1967) approach, in which the literature was consulted after data collection, allowed us to reflect on the collected data without being influenced *a priori* by categories from the literature.

Ethics

The study was approved by the AISSR Ethical Advisory Board of the University of Amsterdam. All staff and family members were informed about the research and the presence of NLD in the nursing home.

Results

We identified four themes in the experiences of professional caregivers: the LCP as a communication tool, systematic symptom management, the complexity of documentation, and limitations of working with the LCP in practice.

Communication at the end of life

Starting a LCP was understood as providing a point of reference to communicate that the end of life of the person with dementia was near:

> I think one of the most important things is often that it [the LCP] becomes a marking point, as in, we are now entering the terminal phase. (elderly care physician)

As such, it is not that the LCP assisted professional caregivers in identifying the end of life, but once a LCP had been started, it was taken as a sign that the person was dying. This marking point was relevant on four levels. First, for nursing staff and elderly care physicians to re-evaluate treatment and start terminal care:

> As soon as it is agreed to start the LCP, we all make a switch and focus on the checklist. I think this provides clarity. […] To have a starting point, this is what we agreed upon, these medicines we keep and those are stopped. (nursing staff)

Second, nursing staff stated that the LCP is relevant in communication with family members, as it raises awareness that the person with dementia is dying:

> I think that for certain family members it [the LCP] provides heightened awareness that things will not get better anymore. (nursing staff)

Third, as a communication tool between disciplines involved:

> [The LCP] helps to maintain continuity between and among all disciplines. That we are all on the same page. (elderly care physician)

Fourth, as a communication tool between shifts:

> After two days off you can go through the previous pages. Also from the night shift, you do get information during the change of shifts but it is always good to be able to check. (nursing staff)

Most professional caregivers indicated that the LCP tunes actions towards a common goal of comfort. Underlying is the assumption of a shared understanding of the care that should be prioritized in this phase.

NLD observed that in practice, each unit used and communicated the LCP differently. In some units the LCP was placed on the resident’s nightstand and openly discussed with family members. In other units, the LCP was kept in the nurses’ office and although nursing staff confirmed that family members could always access it, family members were not always made aware of its use.

Providing structure

None of the professional caregivers indicated they experienced an improvement in communication with residents due to the LCP. While not contributing to interpreting the condition of a dying resident, the checklist in the LCP did provide a sense of structure and control and strengthened caregivers in the conviction that they had provided all care that was needed.

> I believe only the checklist adds value, as a reminder, did I think of everything? (nursing staff)

> So that you don't forget anything […] since often we are not able to ask the residents themselves here. (nursing staff)

Nursing staff perceived the checklist as a comprehensive tool that clearly marks all the focus points relevant for end of life care. The everyday in the nursing home may be hectic, in which case the LCP was also considered as an aid to maintain continuity through regular monitoring requirements. One nursing staff member emphasized:

> Actually, I find it easy, especially when the group is busy. At least you have fixed moments to monitor. (nursing staff)

Professional caregivers also said the LCP stimulated them to prioritize the care goals listed in the LCP and observe the corresponding symptoms with more attention.

> You do look more consciously at a person. So as to see if they might suffer from a full bladder, nausea or pain. And you do have the checklist for yourself to see, oh pain, medication, is it needed, why? I do think it is a nice system. It just helps me to look more precisely. (nursing staff)

Complexity of documentation

NLD observed it was not always clear when a checkbox could be ticked off. For example, one question in the LCP asks if the available facilities have been explained to the family. With several family members visiting, this evoked uncertainty among nursing staff whether, to tick the box, all family members should have had explanation or only the contact person. In practice, even if information was provided, family members would often inquire about the same issue multiple times. Since the LCP only offers a checkbox ‘accomplished’, nursing staff at times assumed the issue was resolved while it was still unclear to family members. This illustrates how in practice certain aspects of caregiving cannot simply be checked off, indicating the limits of the LCP in grasping the complexity of caregiving.

It was further observed that part one of the LCP was often not filled out, which was considered to be the responsibility of the elderly care physician. This part of the form requires information, for example about non-resuscitation procedures, that had already been documented in the regular individual care record, which is established upon admission in the nursing home as a result of discussions between family members and the elderly care physician. Filling out part one of the LCP is then experienced as duplication of work.

Part two, which consists of the checklist for nursing staff, was usually well documented, but not always on the prescribed times. This can be attributed to the unpredictability of everyday care in which nursing staff is needed on the spot. Not documenting care in the LCP on the set times did not mean that nursing staff was not involved with the dying person. It was observed that nursing staff focused on providing care and would document this in the LCP later, in some cases at the end of the day.

Part three requires information concerning the moment of death, which is also requested in forms for the coroner. This final section of the LCP is then also perceived as a duplication of work. It is also considered pointless, since after the resident has died, the LCP is stored without any further usage.

Further, the uncertain trajectory of dementia makes it difficult to establish exactly when to start a LCP:

> Sometimes we think yes, and the doctor doesn't think so. And then you start it, and then you can stop it. We once had a woman for whom it [the LCP] started three times. How then to explain to the family that this time it's for real? And so the fourth time we were like, let's wait a bit. But then we were too late. (nursing staff)

Both elderly care physicians and nursing staff questioned the usefulness of the LCP in situations wherein a resident died suddenly or after a very short sickbed. Time is then lost in filling out the LCP, without the benefit of regular monitoring and reporting.

> I find it difficult, when do you start a LCP? Normally you can see it coming when someone will die within the next three days, and then you start it. But like this morning, we started it. She declined very fast and died. Should I, in such case, start a LCP? Because now I am still not done filling it all out. (nursing staff)

Starting a LCP is generally experienced as time consuming. Both nursing staff and elderly care physicians stated that the LCP is too extensive. Nursing staff specifically addressed the amount of paperwork involved. According to nursing staff, this is time that could otherwise be spent on caring for residents. Professional caregivers also stated the LCP form has a confusing design with the checklist and reporting in separate sections.

> You see, you have to fill out what happens at what time. A is achieved, and V is variance. When V, you have to explain the reason why, and this part is at the end [of the LCP]. It would be more convenient to have it on the same page. Now you have to browse through it. (nursing staff)

The LCP is not a tool nursing staff use on a daily basis, considering that death occurred in irregular intervals, with at times, no deaths for a number of months among the small number of eight residents nursing staff cared for in the units. In cases where the LCP had not been used for a while, nursing staff indicated that they had to familiarize themselves with it again.

> When it has been a while since you've worked with it, I always find it hard to get into it again. Like, how does it work and what am I supposed to do again? (nursing staff)

Limitations in practical use

In general, it was observed that caregiving at the end of life for people with dementia was less guided by the checklist of the LCP than by the care needs that emerged from the actual situation. Professional caregivers stated that they would provide the needed care, whether or not they have a checklist:

> I do not see the added value [of the LCP]. Normally I would also see things. If someone is anxious I undertake action whether or not I have those forms. You just do it. It does not matter, I mean, you also do that in the period when they are not in the dying phase. If you notice there is something with a resident, you take action. (nursing staff)

One elderly care physician even stated end of life care is at the core of nursing home care. Nursing staff further made clear that they would enter the room of the dying person more regularly than listed on the LCP.

> I think that if we would not have the LCP in the small scale units, that we would take a look very often as well. Because even with the LCP we enter the room every half hour, is someone still comfortable, isn't the sun in their face? Yes, we so often just walk in, because it is such a small entity and I find that very pleasant. Sometimes you care for someone for years and they become, I wouldn't say family, but they become sort of your own. (nursing staff)

They stated that when symptoms were observed they would not wait until the scheduled check-up time, but act immediately.

> On a moment like that you act on the spot. Short of breath, or whatever, pain, you call a physician and make sure everything is all right. It's little things, but is she sweating under a blanket, cover her with a sheet instead. That goes without saying, you do not need a list for that. (nursing staff)

Observations in the nursing home confirmed that nursing staff monitored the residents on a more regular basis than required by the LCP. In this way, immediate care needs were prioritized over the checklist in the LCP.

It was also observed that nursing staff would work overtime when the situation required. For example, a nursing staff member who had lost her father a couple of months before found it difficult to support and care for a dying resident. She was starting her shift and was in tears in the kitchen, upon which her colleague whose shift had ended offered to stay with her. In this way she was able to continue everyday care for the other residents while her colleague could focus on the dying resident. Again this indicates that nursing home staff was and needs to be responsive to the situation, and that situations can demand more than just the symptom management addressed in the LCP.

Discussion

The LCP is both useful and at times redundant in the context of caregiving at the end of life with dementia in a nursing home setting, and further consideration is needed regarding whether and how it can be improved to become an optimal tool in this context.

The idea to have all information concerning a resident, including medical treatment plan, the resident's preferences, agreements with family members, provided care, and bereavement care in a single document is valuable. However, the LCP causes duplication of work because much of this information is already documented in the regular care record and official documents present in the nursing home. There was a consensus among professional caregivers that using the LCP was unnecessarily complex and did not fit well with the nursing home setting or the context of dementia. While most professional caregivers admitted seeing both positive and negative aspects to the LCP, we did not find patterns in the ways in which the different professions or units valued the LCP as useful.

As mentioned above, one of the criticisms on the LCP in the UK has been that it was often used as a protocol or 'tick-box exercise' (Neuberger, 2013). We recognise that in the Dutch context it was used as a checklist to the extent that for some professional caregivers the LCP was mostly a bureaucratic obligation. For others it was mainly a tool that served as a reminder of symptoms to look for. In line with Gambles et al. (2006) and Duffy et al. (2011) we found that, in practice, nursing staff acted upon the care needs that emerged in the moment, which means the person with dementia, rather than the checklist, was the point of reference in everyday care.

Similar to Jack et al. (2003), our study observed that the LCP was appreciated by nursing staff to the extent that it gave them a sense of having done everything within their reach to provide comfort to their residents. By structuring caregiving, the LCP provides a sense of control in the uncertain trajectory of dying with dementia. Providing comfort at the end of life with dementia can be complicated, as often, residents with dementia cannot verbalize discomfort or pain (even if nonverbal communication is still possible). In this challenging context, the LCP directs the professional caregiver's attention towards the listed symptoms, but it does not provide nursing staff with the means to better evaluate these. This remains a subjective task in the hands of professional caregivers.

The results show that, as the required and provided care are documented in the LCP, it may also be considered a means of communication between different disciplines and sometimes family members (Jack et al., 2003; Clark et al., 2012), in this way contributing to a continuity in care (Gambles et al., 2006). Specifically, starting a LCP means communicating the onset of the dying phase. While it does not support professional caregivers in identifying the end of life itself, once a LCP is started it invokes awareness that the resident is dying. In line with Swart et al. (2003), we consider this one of the LCP's benefits. As such the LCP offers a sense of certainty in the uncertain trajectory of dying with dementia. However, because the trajectory of dementia is hard to predict (van der Steen et al., 2011; Brown et al., 2013; Davies et al., 2015), it is also difficult to estimate accurately when to start a LCP. This may also be the case with other populations (Watson et al., 2006; George et al., 2014; DiLeo et al., 2015). If a LCP is stopped because the resident improves, this sense of certainty and control turns out to be misleading. When dying proceeds rapidly, professional caregivers still spend a lot of time filling out the LCP that would be better spent caring for the dying resident (DiLeo et al., 2015). In the context of dementia, the LCP may have benefits but this depends on the individual trajectory of dying.

Overall, we agree with George et al. that underlying the LCP there is the assumption “that human complexity is reducible” (George et al., 2014: 4). We find that the LCP fails to address the complexities of caregiving in the specific context of dementia care in nursing homes, which involves above all paying attention to a resident’s needs and thus knowing how to achieve comfort for that specific person. We should be aware that the efficient use of tools such as the LCP is not being confused with the need for responsive and person-centred care. Therefore, we should not cease to consider, in the further development of the LCP, whether and how its benefits as a reminder and a communication tool are balanced with the burdens of its use, such as the amount of work it requires.

Limitations and strengths of the study

Considering that this study was undertaken in a single nursing home, we do not aim at proposing generalisations on the use of the LCP in the Dutch context or nursing home settings, but to highlight possible complexities of its use in practice.

The presence of NLD in the nursing home can be considered both a strength and a weakness of this study. On the one hand, the researcher’s presence may have influenced informants to adapt their conduct due to being aware of the research focus. On the other hand, it allowed the researcher to directly address and observe actual use of the LCP in practice. The combination of observations, interviews and informal conversations allowed the authors to analyse both how professional caregivers expressed their experiences of, and used the LCP in practice.

Recommendations for practice and research

If nursing home staff wishes to use the LCP, then its usability in everyday caregiving should be improved. Along these lines, we find that the specific context of implementation of the LCP should be taken into account (Watson et al., 2006). For example, the requirement to check on a dying resident every four hours may be helpful in some settings, but in a nursing home unit with only eight residents, professional caregivers usually walk in and out of the rooms much more often, making such a schedule arbitrary, if not redundant. Accordingly, a pathway should be developed that is more compact (Venkatasalu et al., 2015), flexible, and that can be included in the regular care record instead of a detached and overly extensive document, to better fit the particularities of the nursing home setting. This effort could be combined with existing symptom assessment tools for people with dementia (Lichtner et al., 2014; Ellis-Smith et al., 2016). Rather than having a system in which boxes need to be checked, and thus considered done, it would be better to have reminders and guidance for observing symptoms that allow for uncertainties and ambiguities that change in the situation of the dying person. In addition, possibilities for nursing staff to refresh their user knowledge of working with the LCP should be offered (Gambles et al., 2006; Brännström et al., 2016).

For further research we recommend the study of how family members experience the LCP in end of life care. It would also be interesting to examine implementation and effects of other end of life tools to compare findings.

Conclusion

The LCP can be valuable but also at times redundant in the context of caregiving at the end of life with dementia in a nursing home setting. The LCP was not employed as a rigid structure as it was observed that nursing staff acted upon the care needs of the dying residents rather than following the checklist in the LCP. From working with the LCP, in particular the checklist, nursing staff derived the recognition that care was well provided and none of the required tasks were overlooked. In this way, the LCP reassures by establishing a concrete framework of symptoms to focus at. In this sense, nursing staff experienced working with the LCP as supportive. However, there should be awareness about its limitations in practical use. In its current form, the LCP is unnecessarily complex and does not fit well with the nursing home setting or the context of dementia.

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Declaration of conflicting interests

The authors have no conflicts of interest to declare.

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