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Hospitalised Palliative Care – From a Philosophy of Care to Rigid Guidelines for Intervention?

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Key words: palliative care, death in hospital, Liverpool Care Pathway, UK experiences, 'approach' versus 'guidelines'

Introduction

Palliative care developed from hospice philosophy, which considers dying as a natural process to be recognised as an important part of life and taken into account in the health care system. Cicely Saunders developed hospice philosophy from the idea of providing a place for end of life care to an approach to care that could be applied wherever dying people are encountered. In the United Kingdom there has been an urgent discussion about emerging evidence that the attempts to transfer key principles of palliative care into acute hospitals have, in many respects, been a failure. The evidence suggests that, even against a background of maturing palliative care, a serious challenge remains for the management of the last hours and days of life, when health care is predominantly 'cure' oriented and managerial in process. Drawing upon the UK's experiences with the Liverpool Care Pathway (LCP), this article will discuss some of the paradigmatic tensions which can appear when a palliative care approach is moved into mainstream health care in the hospital. It is timely to reflect upon such challenges as Denmark (as well as other Nordic countries) faces a similar demand to expand its much less mature palliative care in a similar direction. The lessons which can be learned from the UK are perhaps also common to other national contexts and might therefore serve as a valuable source of inspiration. This article thus provides critical reflections on the uncritical adoption of the UK experiences.

Palliative Care as an Approach

As part of the so-called 'death awareness movement' that arose in the 1960s, the modern hospice movement developed out of a recognition that main-stream health care was failing to care for dying people in a medical system focused almost exclusively on cure, which as a consequence of considering death a failure or a 'scandal of reason' (1) ignored the importance of the last part of life and failed to understand how good care can comfort dying persons (2). Cicely Saunders believed that values grounded good care and emphasised these frequently in her writings. She regarded the hospice movement as the creation of a space for values to move into the care for dying people. The ideal was to help dying people to a good death, which involved values such as an open awareness of dying, acceptance, painlessness, and family involvement (3). Care, based on an ethical approach driven by compassion and directed by the needs of the dying individual, was seen as a crucial starting-point for palliative care; as Saunders put it: "The interesting fact in care for the dying is not 'why' but 'what'." (4) This approach placed less emphasis on the diagnosis than on what can comfort the dying person, recognising that pain is a whole experience ('total pain') with the values which gave substance and meaning to care - that death becomes a process to be managed rather than a truth to be confronted. She emphasised that medical science is the basis of palliative care, but, if unrelated to the original ethics, palliative care would risk losing its ethos (8). Thus, an already existing tension within palliative care is the one between the ideal of holistic care for the dying

aimed at helping dying people to achieve a 'good death', on the one hand, and the reductionist focus on symptom control based on the idea of isolation of the specific symptom in order to explain and eventually control it, on the other. As we will discuss below, this tension becomes most salient when attempting to transfer palliative care to an acute hospital setting.

Palliative Care –From Hospices to Hospitals

Although the UK has one of the most long-standing and advanced palliative care services in the world,

the advances in applying a comprehensive palliative care service have been relatively modest and piece-meal. It is curious that the problems encountered by dying people and their families, and the strategies to deal with them, were already extensively described in the 1950s.⁹ Despite this, the same issues featured in UK policy initiatives in the 1990s. The Calman/Hine Report (DH 1995) established a framework for cancer services across England and Wales, which was one of the first strategies to give impetus to palliative care and its integration with cancer services. Further impetus was given by the NHS Cancer Plan from 2000, which promised to increase the standard of care for the dying. When Jane Seymour in 2001 catalogued the continuing failure of medicine to deal humanely with dying people,¹⁰ this work added to the established and growing body of work with a similar litany of complaints about mainstream health care that inspired the first hospices. Moreover, several later studies have documented some of the deficiencies and drawbacks involved in the increasing bureaucratisation, routinisation and medicalisation of the hospice system itself.¹¹ So, although the palliative care community for quite some time seems to have known what it ought

to be doing, there has apparently been a problem in translating this knowledge into other contexts.

More recently, the National Health Service's (NHS) end-of-life care programme and the National Services Frameworks from 2003 and 2006 have incorporated aims for appropriate end-of-life care across other chronic diseases and for older people. In 2005, the NHS Confederation published a summary of government and wider agency responses to the challenge of improving end-of-life care, which went a long way to reconciling some of the tensions that existed between mainstream healthcare and palliative care, between terminal care and palliative medicine and between cancer and other chronic progressive conditions that might result in the need for palliative care. It is acknowledged that end-of-life care is part of a much wider area of palliative care and that there is a need to galvanise services and resources across the health and social sectors to meet the increasing needs of an ageing population. What is significant about the response is that it incorporates many of the principles and complex cases through specialist palliative care, but also to disseminate the principles of palliative care so they can be utilised wherever there is a need for managing end-of-life care.¹²

The LCP was originally designed in order to ensure a good-quality death for people wherever they may die, but with a recognition that instances of dying within an institution – and specifically a hospital setting – would be likely to continue to increase in the future.¹³ The LCP has as its focus the last few days or hours of life and relies upon the clinician being able to predict accurately that a patient is close to death. Within the multi-disciplinary team, communication of the intended plan of care to the patient, if they are able to communicate, but certainly to the family, is seen as an

absolute requirement. The plan of care is underpinned by the palliative care philosophy, which seeks to provide holistic care in an atmosphere of open communication with an emphasis on what Cicely Saunders called 'comfort care', but also to include empirically guided symptom control. The LCP was

"The UK experiences with LCP can be seen as an example of how an approach, turned into a set of instructions, fails to deliver its goals."

values of palliative care into professional standards, guidelines and protocols. Moreover, the General Medical Services Contract of 2004 supports government funding including incentives to general practitioners to specialise in end-of-life care. Also the Gold Standards Framework (GSF) for community palliative care was developed in order to provide a framework for primary care professionals to manage patients in their last year of life. The GSF was supposed to enable support to be given to patients and their carers give access to specialist palliative care, avoid emergency hospital admission and respect the patient's choice of place of death. It was in this context that the Liverpool Care Pathway (LCP) was developed to help generalists to provide palliative care principles in hospital in the last 48 hours of life. The LCP developed out of the experience of a hospital-based palliative care team who wished to draw upon their experiences to devise a so-called 'care pathway', which would enable the principles of good palliative care to be disseminated to, and be used by, non-specialists. This is in keeping with palliative care's strategy to manage the more specifically designed with the generalist in mind following the long-held aspiration of the palliative care community to disseminate the principles of palliative care more widely.

There are certain parallels to the UK situation in the way in which Danish palliative care has developed over the years. However, in Denmark palliative care developed later than in the UK. The hospice philosophy was initiated in public health care in the late 1980s and the first hospice was established in 1992 – whereas in the UK the first modern hospice opened in 1967. The National Health Service in Denmark distinguishes between 'basic' palliative care, referring to the end of life care as delivered by hospitals and General Practitioners, and 'specialised' palliative care, as delivered by hospices and palliative care teams.¹⁴ Today, 19 hospices have been established and outward specialised palliative care teams support dying patients at home and perform an advisory role for health care professionals at a basic level of palliative care. Moreover, palliative care wards have been established at some hospitals. Like in the UK, Danish pal-

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Palliative care services face the problem of disseminating the principles of palliative care beyond the context of terminal cancer and to extend the reach of palliative care to all contexts where chronic progression diseases are managed (e.g. heart failure patients, people suffering from severe dementia or people with chronic lung disease (CLD/KOL). There is a strong and continued need for organising basic palliative care and for securing more cooperation with specialised palliative care units concerning areas regarding the development of care as well as in the development of staff competences and research. ¹⁵ Ongoing project into the development of evidence-based national clinical guidelines for palliative care has been initiated by the Danish Multidisciplinary Cancer Group (DMCG pal), and there are also a number of local initiatives that use the Liverpool Care Pathway as a

tool for palliative care practices. 16 So given that the LPC and similar 'guide- lines' are being considered as appropriate means for achieving these objectives, it is imperative that Danish palliative care does not repeat the mistakes and inexpediencies of the UK experiences, some of which will be discussed below.

The Liverpool Care Pathway and the UK Debate

Following a series of well-publicised complaints and 'horror' stories published in the popular UK media,¹⁷ the Department of Health appointed a review panel chaired by Baroness Julia Neuberger. The findings of the panel were published in 2013 under the title "More Care, Less Pathway: A Review of the Liverpool Care Pathway". Although the panel received evidence and testimony that the LCP did indeed enable a peaceful and dignified death for many patients, the outcome was nevertheless highly variable between institutions and between personnel. In brief, the panel uncovered a number of problems ranging from ambiguity in the meaning of key concepts like 'end of life', which can mean anything from the last year of life to the final days or hours of life, to the fundamental challenge of predicting or diagnosing 'dying' – the point at which the emphasis of the treatment plan may be justifiably changed. There were many complaints from families that the decision to place their loved one on the LCP was premature. There were also many instances when the decision to change the emphasis of treatment was not communicated to family members, who therefore sometimes returned to the hospital to find the patient heavily sedated and seemingly abandoned. On some occasions the interpretation of LPC was so brutally literal that a patient who was capable of swallowing was denied fluids by mouth because 'artificial hydration' had been withdrawn. For example, 90 year-old Kathleen Vine expressed her experience of LPC as: "All I remember is they weren't feeding me. Up above my bed they put 'nil by mouth' and I was begging for food."¹⁸

The nature and number of corroborated complaints that came before the panel amounted to a catalogue of neglect, which became a damning indictment, not of the LCP itself but of its implementation into hospital care. Since July 2014, the LCP has been completely phased out. The report *One Chance to Get It Right*, published by Leadership Alliance for the Care of Dying People (LACDP 2014), has replaced LPC and sets out an approach to caring for dying people that health and care organisations and staff caring for dying people in England should now adopt. This approach does not set out a protocol or process that has directly replaced the LCP, but instead details the ways in which care for people who are dying should be responsive to the overall needs and wishes of individuals and their families. It identifies five priorities for care necessary to achieve good quality care in the last days and hours of life. These priorities refer to virtues and values of importance in professional care at the end of life. The five principles reflect traditional values of palliative care such as open awareness of dying, family involvement, painlessness and compassionate care, all of which are similar to the original idea of LPC.¹⁹ There seems to be a consensus about the relevant values which underpin palliative care evident in both the LCP and the new principles. The main difference, however, is the change of terminology from 'pathway' to 'principles'. This change must be seen as an attempt to avoid an understanding of palliative care as a set of pre-determined and rigid instructions rather than a way of engaging with the needs of individual patients and their families at the end of life. However, the challenge is still to establish the best means of using such principles so that health care professionals are able to deliver quality care for dying people within mainstream healthcare.

Several challenges of transferring palliative care from the hospice into the context of hospital health care can be identified from the UK experiences briefly mentioned above: How to implement a care

approach based on principles and values and not rigid guidelines in a hospital system, how to fit in palliative care with a system usually focused on cure, and how to educate staff properly to be able to incorporate a palliative care approach as part of their professional practice. These challenges are still to be faced in the UK. It should also be observed that several of the serious problems with LCP were not merely due to neglect and poor judgment, but presumably also point to more serious philosophical and sociological challenges with the LCP and the nature of palliative care in general. Simon Woods' critique of palliative care's history and values has pointed to the considerable challenge palliative care faces in articulating a model of care that is capable of providing robust and normatively credible accounts of the appropriateness of the changing objectives of care across the illness trajectory.²⁰ An important question in this respect seems to be: can dying be 'diagnosed'? And if it can, then what forms of care are/are not appropriate during the dying phase? As the critique of LPC has emphasised, diagnosing dying is a complicated matter and it might not always be possible or appropriate to make a definitive diagnosis of 'dying'.²¹ When to end treatment and start palliative care in a context of cure is in the last instance a clinical judgment, involving the wis

a gross deviation from palliative care values, yet the experience in the UK has shown that a care 'pathway' can have such negative influence.

A key flaw in the implementation of the LCP was the lack of training of the personnel who were to use it, as was pointed out by the Department of Health as well as by the LAPDC report. A review of the LCP finds that key factors for successful implementation were: a dedicated facilitator, education and training, audit and feedback, organisational culture, and adequate resources, all of which indicate that a successful implementation of palliative care demands more than the dissemination of a set of principles. Success requires the creation of a professional culture which enables health carers to internalise the values of a palliative care approach. To adopt an ethical approach and navigate in the field of end-of-life care thus demands an attuned capacity for clinical judgment and practical knowledge of ethical and existential issues at the end of life. Clinical guidelines addressing, for example, sedation do not tell the practitioner about the specific concerns the family might have as to whether it is

"Principles require good judgment in their application whereas a blind use of principles as instructions can result in the obvious wrong of a patient."

hes of the dying person and relatives as to when, how and if palliative care values such as open awareness of death and a peaceful death are introduced and how they should be interpreted. The UK experiences have displayed that 'dying' is difficult to diagnose and not necessarily accepted as a forthcoming event either by relatives or by dying persons who might have an expectation to continue curative treatment. A transition from cure to palliative care must therefore take into account that palliative care values such as open awareness have to be balanced to the concrete situation and the readiness of different families, acknowledging that death and dying are distressing subjects for those who are personally involved. The application of principles needs a skilled workforce, able to navigate a way to 'open awareness' while showing respect for the difficulty and uncertainty of recognising dying as an existential fact. To merely follow the principle of open awareness as a 'top-down' directive is likely to lead to insensitive and potentially brutal approaches. Forcing open awareness upon the patient and family would be

considered as a mean of inducing a 'peaceful end' or is regarded as a potential means of quieting the patient and hastening death. Demonstrating good judgment in such situations demands an ongoing training in achieving practical knowledge, which enables the practitioner to interpret what is appropriate for a specific family in the specific context. Such skills are difficult to acquire if compassionate person-centred care directed towards comforting dying people in their suffering is not recognised and valued as an integral part of the clinical approach.

The practical challenge of preparing a workforce adequate to the task of delivering compassionate care to dying people must be addressed if the unfortunate experiences with LCP in the UK are not to be repeated in the Danish context.

Concluding Remarks

An important lesson to be learned from the UK experiences with transferring palliative care into a hospital setting refers to the paradigmatic tension we have touched upon earlier as already existing within palliative care. The tension is created by two different ways of thinking about palliative care: (1) Palliative care as ruled by a set of rigid instructions used by a rational symptom-oriented clinician in order to deliver palliative interventions as efficiently as possible versus (2) palliative care as an approach adopted by a judging practitioner in order to comfort the individual dying person in his/her suffering using palliative care interventions as tools towards well-judged ends. The UK experiences with LCP can be seen as an example of how an approach that is turned into a set of instructions fails to deliver its goals. Perhaps the fatal flaw in the LCP is that it was rolled out as a management tool rather than as a framework of general principles to guide good clinical judgment. The evidence suggests that it was sometimes blindly used as a set of instructions and prescriptions rather than as guiding principles. The difference between these two interpretations is crucial to the approach taken. Principles require good judgment in their application where- as a blind use of principles as instructions is like the 'tail wagging the dog' and can result in the obvious wrong of a thirsty patient being denied a drink because artificial hydration is not indicated. This echoes Ann Bradshaw's earlier concern about developments in palliative care itself, that care might become mere 'technique' devoid of values and be transformed into what Michael Kearney mentioned as 'just another speciality' occupied with solving 'the problem of dying' instead of trying to help dying people and their families, if possible, to find meaning in the suffering at the end of life. Our suggestion is that even though there might be certain lessons to be learned from LCP and other similar programmes, it is important to continue to appreciate palliative care as an approach to or a philosophy of care that cannot simply be reduced to rigid guidelines or manuals for intervention.

Notes

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2. See, e.g., Simon Woods (2007): *Death's Dominion – Ethics at the End of Life*. Buckingham: Open University Press; and Michael Hviid Jacobsen, Louise Lund & Vibeke Poulsen Graven (2013): A

Revival of Death? – Death, Dying and Bereavement in Contemporary Society. In Michael Hviid Jacobsen (ed.): *Deconstructing Death – Changing*

Cultures of Death, Dying, Bereavement and Care in the Nordic Countries. Odense: University Press of Southern Denmark, pp. 27–54.

3. See, e.g., Vibeke Poulsen Graven (2015): *Hospice- filosofi i praksis*. Eksistentiel/åndelig omsorg for døende på hospice. Aalborg Universitets Forlag. Phd. serie: Det Samfundsfaglige Fakultet. Aalborg Universitet; and Shirley du Boulay (1984): *Cicely Saunders*. London: Hodder & Stoughton.
4. Cicely Saunders (2005): *Watch with me*. Inspiration for a life in hospice care. Lancaster: Observatory Publications, p. 3.
5. Cicely Saunders (1996): *A Personal Therapeutic Journey*. In Cicely Saunders: *Watch with me*. Inspiration for a life in hospice care. Lancaster: Observatory Publications.
6. Cicely Saunders (1996): *A Personal Therapeutic Journey*. In Cicely Saunders: *Watch with me*. Inspiration for a life in hospice care. Lancaster: Observatory Publications, p. 36.
7. Michael Kearney (1992): *Palliative Medicine – just another specialty?* *Palliative Medicine*, 6(1): 39–46.
8. Ann Bradshaw (1996): *The Spiritual Dimension of Hospice: The Secularization of an Ideal*. *Social Science & Medicine*, 43(3): 409–419.
9. See, e.g., Joint National Cancer Survey Committee of the Marie Curie memorial and The Queen's Institute of District Nursing (1952). *A report on a national survey concerning patients with cancer nursed at home*. London, Marie Curie Memorial; and Hughes H.L.G. (1960): *Peace at the Last*. *A Survey of Terminal Care in the United Kingdom*. London: The Calouste Gulbenkian Foundation.
10. Seymour J.E. (2001). *Critical moments – death and dying in intensive care*. Buckingham. Open University Press.
11. See, for example, Nicky James & David Field (1992): *The Routinisation of Hospice: Charisma and Bureaucratisation*. *Social Science & Medicine*, 34(12): 1363–1375; and David Clark (2004): *Between Hope and Acceptance: The Medicalization of Dying*. *British Medical Journal*, 324(7342): 905–907.
12. For more on these different initiatives and programmes, see: Ellershaw J.E. (2002): *Clinical pathways for care of the dying – an innovation to disseminate clinical excellence*. *Journal of Palliative Medicine*, 5(4): 617–623; Ellershaw J.E., Ward C. (2003): *Care of the dying patient: the last hours or days of life*. *BMJ*, 326: 30–34; Ellershaw J.E., Wilkinson S. (2003): *Care of the Dying: A Pathway to Excellence*. Oxford: Oxford University Press; and Thomas K. (2003): *Caring for the dying at home: Companions on the journey*. Oxford, Radcliffe Medical Press.
13. Barbara Gomes, Higginson I. J. (2008): *Where people die (1974–2030): past trends, future projections and implications for care*. *Palliat Med* January 2008, 22: 33–41.
14. Sundhedsstyrelsen (2011): *Anbefalinger for den palliative indsats*. Copenhagen: Sundhedsstyrelsen.

15. Sundhedsstyrelsen (2011): Anbefalinger for den palliative indsats. Copenhagen: Sundhedsstyrelsen; and PAVI (2013): Hospitalernes palliative

indsats på basalt niveau. Copenhagen: Palliativt Videnscenter (PAVI).

16. See: <http://www.pavi.dk/Kvalitetssikring/lcp.aspx>.

17. See: MailOnline <http://www.dailymail.co.uk/news/article-2363543/Catalogue-abuse-killed-Liverpool-Care-Pathway.html>

18. See: <http://www.bbc.co.uk/news/health-23698071>.

19. Leadership Alliance for the Care of Dying People (LACDP) (2014): One Chance to Get It Right. London: LACDP, p. 12.

20. Simon Woods (2007): Death's Dominion – Ethics at the End of Life. Buckingham: Open University Press.

21. Leadership Alliance for the Care of Dying People (LACDP) (2014): One Chance to Get It Right. London: LACDP, p. 17.