BOOK REVIEW

Hayes, E.L. (2014). Pathways through Care at the End of Life. London: Jessica Kingsley Publishers. ISBN 978-1-84905-364-8

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Introduction

There is plenty of evidence that there is much to be done in opening up the topic of death and dying, amongst health and social care professionals as well as amongst the wider society and general public. For example, there is evidence that we are better at talking about cancer and palliative treatments or end of life care than about death itself. People being treated for cancer still complain of friends dropping away and wear an uncomfortable wig in a public place rather than face the stigmatising experience of no-one coming to sit next to them because of their appearance. Bereaved people describe acquaintances crossing the road rather than having to speak to them. The need to tackle the continuing fear and taboo of death has led to the establishment of various charities in the UK in recent years. For readers who are learning about pathways for care at the end of life, this guide to person-centered care clearly explains the terminology associated with this practice. We are shown how palliative care and end of life care coalesce. The centrality of communication is shown in advanced care planning particularly when all of the professionals involved are working together in multi-disciplinary assessments.

The intended audience and the style of writing

The intended audience for the book is all of the different professionals involved with people who are caring for, or related to, people who have been placed on pathways to the end of life. The style is accessible and supported with short case studies in order to demonstrate the personalisation of practice and it frequently poses direct questions to the reader. In the chapter on discussions as the end of life approaches, the question is, for example, "What things inhibit you in opening conversations about end of life care?" There are also text boxes addressing specific themes in each chapter such as "Opportunities for end of life conversations", "Attitudes and assumptions", "Features of psychosocial care" and "Advocating for a person's right to choose" and many other invaluable concise analysis of care. These boxes also include emotionally moving case stories. Throughout the book there are lively considerations of information transfer and communication amongst providers and between providers, individuals and their families. These also lead on to discussions of the holistic assessments that can be carried out and barriers which can arise in care planning. The book is full of excellent thoughtful thinking tips such as: "Is your practice centred on the needs of the person or on running an efficient system?" "How can these two objectives be brought together?" These are highlighted with the advice: "Stop and think". After clearly discussing the end of life care, the question is posed: "How do you understand the difference between palliative care and end of life care?"

Definitions

The book presents and discusses the WHO Definition of Palliative Care. Palliative care is appropriate when a person is at the point in their illness where the treatment objective is *care,* not *cure.* Its starting point is a medical diagnosis and it also encompasses the psychological, emotional, social and spiritual needs that may accompany a terminal illness. The authors of this particular chapter within the volume provide a working definition of end of life care: "End of life care is the care provided to a person in their final stages of life, which includes but is not limited to the period when death is imminent. It is care that helps those with advanced, progressive, incurable illness or extreme frailty combined with one or more chronic health problems, to live as well as possible until they die. The end of life care phase may last for weeks, months or years. It includes the management of pain and other symptoms and the provision of psychological, social, spiritual and practical support. It is person- centered and extends to support of the family and other carers including into bereavement." Unless end of life care is embedded in routine practice, the goal of quality care for everyone at the end of life will not be achieved.

However, as the volume explains, it has gradually emerged that the palliative care approach is equally appropriate and beneficial for a large group of people whose condition is not labelled as 'terminal', although it is recognised that they have a life-limiting condition. Moreover, the end of life phase for such people may last months and sometimes years and the care they require is not limited to relief of physical symptoms, but it is, nonetheless, associated with the end phase of their life. This shift largely arises from the demographic changes affecting all of the countries of the developed world. With increasing populations of older people, most particularly those over the age of 85 and given advances in medical technology and treatments in the Developed World, people can live longer, even with serious illness and disease. People may have a range of medical and health, social, emotional and spiritual needs over this period and they may require palliative care if death is imminent. The defining nature of this book is that it explores these end of life journeys, their unique features and common patterns and the care and support that health and social care services can offer to ensure that quality of life is as important at the end of life as at any other time.

The volume considers holistic assessment to be 'characterized by the belief that the parts of something are intimately interconnected and explicable only by reference to the whole'. In the context of medicine, holistic care is 'characterized by the treatment of the whole person, taking into account mental and social factors, rather than just the symptoms of a disease'. The assessment of a person at the end of life must therefore consider: 'Who is this person in front of me?' 'What are their needs in relation to their condition?' and 'Who is important to them?' The holistic common assessment, as the volume makes clear, consists of: background information and assessment preferences; physical wellbeing; social and occupational wellbeing; psychological wellbeing; spiritual wellbeing and life goals. It is through careful consideration of the person's needs in relation to each of these domains that a holistic assessment can be made and a care plan formulated. Each of these domains impacts on the others and a holistic assessment takes account of this. As physical symptoms affect psychological wellbeing, an integrated assessment of need is as the book emphasizes, required.

Discussions as the end of life approaches

Researchers have proposed that professionals should develop a method of communication to continuously check understanding and to keep establishing what information the person needs. It is also important that workers consider how they impart information and the language they use. Factual information or supportive words and phrases may be misunderstood or simply not be 'heard' and received in the way the worker intends. Advance Care Planning (ACP) is an essential component of the care planning process. It is about ensuring that an individual's wishes and preferences remain at the centre of support, care planning and service provision. ACP can be a stand-alone process that specifically concentrates on a tool to record wishes and preferences, or it may be part of ongoing discussions with the individual.

Advance care planning (ACP), as the volume describes, is a way of ensuring that an individual can discuss, identify and have documented their preferences for care and preferred place of death as the end of their life approaches. These discussions and the recorded information should be revisited and revised as appropriate as the person becomes more unwell. It is important that the person and their family be aware that the plan is an ideal and although every effort will be made to achieve these preferences, limited resources and restricted access to certain services at times may require a change to the plan. It is important to remember that ACP conversations are voluntary and whilst some of these conversations may be difficult, they are in fact conversations, which assist and can empower the individual. The conversations can help ensure that individuals retain some control and that it is their own wishes and preferences that remain the focus of care planning. It is important that all those involved know what the person's wishes are and how they will contribute to the person's care. Information sharing, with the individual's consent, will be necessary to ensure that the wishes the person has articulated are taken into account and achieved where possible. The volume discusses all such factors in admirable detail.

Assessing need and planning care

A central theme of the book is identified in Chapter 3 on assessing need and planning care. There is no identifiable optimum time to assess the situation and needs of an individual and their carers and, additionally, there is not always a clear time at which an individual's needs are classified as palliative. The end of life is not classifiable simply as the last days or hours of a person's life. Rather, planning can start from the point of diagnosis. The most important factor is that a comprehensive, integrated and holistic assessment be undertaken at some point. This must be timely for the individual - that is, when it is identified that they are currently in need of information, support and services. The responsibility for identification of the need for assessment falls to the professionals or care worker working with the individual at the time. This is where difficulties can occur in that, at times, assessments are overlooked or viewed to be someone else's responsibility in the health and social care 'chain'. The starting point for an individual approaching the end of life occurs at as early a stage as possible and then undertaking a holistic needs assessment for potential needs, wishes and preferences. At this stage it is critical not only to develop and record a care plan but - with the individual's consent - to communicate this to all those professionals and agencies that will be involved in the individual's care. Given the rapidly changing and often unpredictable, nature of the end of life phase, these plans should be revisited and communicated at regular intervals. This is where multidisciplinary teamwork

is especially important. All of the professionals involved in the individual's care need to be aware of what is happening. Again, the volume discusses all such factors with admirable clarity.

One of the most basic skills in an assessment is gathering information. Communication may be with people who speak another language, cannot speak, cannot hear, cannot see or understand. Information relating to the individual in terms of contact details for themselves, family, next of kin, current healthcare conditions, GP/family doctor and any care services already in place has to be recorded. There are many consequences of not completing a holistic assessment. Quite simply, it may prevent the needs of the person at the end of life being identified and the best possible care and support being put in place to address those needs. Further, the person's opportunity to make informed decisions about care planning will be undermined and communication between workers caring for them will be compromised. Most importantly, the individual may not experience a dignified death that reflects their choices and wishes and for those left behind, the experience of their loved one's death could be one of anger and complaint. Simply put, without an integrated, holistic approach to end of life assessment and care planning, we would fail to serve the needs of the person at their most vulnerable. Good assessment practice, on the other hand, is an empowering process that facilitates a dignified end to their life in whatever way is right and appropriate for the person. As the book makes clear, key questions which need to be addressed to achieve quality in end of life care include: 'What systems are in place to monitor and evaluate the quality and delivery of end of life care?' How do both the organisation and the practitioners handle feedback from the people in their care and their families?' 'Are complaints dealt with speedily and with respect?' 'Do you have a system for noting what is valued?'

In relation to spiritual issues in particular, some health and social care professionals may feel out of their depth. All practitioners have to be sensitive to the spiritual needs of the other person and of their significance in relation to the assessment as a whole. However, they should also know when to refer and whom to refer to when they have reached the limit of their own capacity to understand and respond. An integrated, multidisciplinary approach means that every worker who supports and provides interventions for the person at the end of life keeps the wholeness of the person and their situation uppermost in their mind.

As the book describes, it is important to be aware of the barriers that can prevent holistic assessments from being adequately completed. Workers may feel that they are taking away someone's hope by assessing their current and future needs and thus undertaking and end of life assessment is avoided as a 'difficult conversation.' Key to the successful completion of a holistic assessment is the worker picking up on what could be termed 'social clues'. Medical staff and clinicians rely heavily on clinical triggers or physical symptoms as a benchmark for what is happening to the individual. When considering the co-ordination of care, the authors of Chapter 4 of the volume explain that key challenges arise when there is a lack of information transfer and communication amongst providers and between providers, individuals and their families. The need for 'joined-up' care at the end of life is widely recognised and some of the best innovations and exemplars are to be found within cancer care. Integrated care models need to be flexible and supported by clear, well-considered protocols and operational policies for delivery. For example, it is increasingly the case that care home residents wish to die within their adopted home - but this requires co-operation and information sharing among care home staff, GPs/family doctors, community nurses, out-of-hours services, ambulance staff, social services and hospitals. In the case of a hospital, an individual wanting to die at home may require the help of a rapid discharge team as well as many support services in the community to achieve their wishes. All of these services need to be available and to be ready to respond swiftly.

Multidisciplinary team working

When co-ordination of care does not happen as it should, the consequences can be devastating for both the individual and his or her family. Fundamental to 'getting it right' is to ensure that a multidisciplinary approach exists, is resourced and that it is operating effectively. There are many examples of excellent multidisciplinary team (MDT) working in end of life care, particularly in the field of cancer care from where palliative care initially developed. The key characteristics of effective multidisciplinary team working in cancer care have already evidenced the importance of having operational policies for how the multidisciplinary team should work. These should include identifying the key workers, the range of people/organisations involved, issues of consent and regularity and the format of meetings. Once an individual's care plan has been agreed upon, it is important that all those involved in the MDT are kept updated and that, where possible, they attend regular meetings. Multidisciplinary team working can be real or virtual to enable groups of professionals needing to communicate indirectly, rather than face to face, where circumstances, such as large geographical distances between services, exist. Equally important is the need to provide support, care and access to advice 24 hours a day, seven days a week. Arrangements must be agreed upon from the outset to ensure that support is available in the middle of the night or at weekends. It should be borne in mind that different elements of an individual's care may need to be co-ordinated by different people, depending on their complexity.

Given that multidisciplinary teams will operate differently, of the chapters who consider these issues the authors identify some of the core principles that remain the same. For example, there should be a holistic approach to the assessment of need and delivery of the person's care; therefore the team should consist of all professional disciplines and sectors of serviced provision with a balance of team composition and skills. Communication about end of life care takes place during the family conference which

is attended by family members as well as the Intensive Care Unit team. Doctors can use open-ended questions with the patient and family in order to ascertain the extent of knowledge of the patient's situation. This process includes finding out how each patient would want to receive information, including the right of a patient to decline receiving information. This must be person-centered, rather than led by the norms of a person's religious or cultural affiliation and, ideally, should take place from the outset. Establishing goals for care and treatment priorities and finally establishing a care plan. It is vital for everyone to have a clear understanding of accountability knowing who is responsible for different aspects, ranging from clinical and practice decisions to direct delivery of care.

Underpinning any multidisciplinary system has to be effective and prompt communication and information sharing across all sectors. At the heart of any system sits the individual and their family. Everyone in the MDT needs to communicate openly and honestly, not only with one another, but also with the individual and their family, according to the principle of 'no decision about me, without me'. Although flexibility and working across boundaries are key elements in successful MDT working, it is also important that every team member knows his or her role within that team and that there is an awareness of the limits of that role and when handing over of responsibility to someone else should occur. In addition, all team members need to recognise that this is a significant and often traumatic time for the individual and their family. They should try to offer them emotional as well as physical support in whatever way they can - as well as remembering the need to support their colleagues. At heart, this is a matter of showing empathy and kindness.

Delivery of high quality care in different settings

There comes a point for many people where they may need end of life services in a number of care settings or require integrated care in one setting. Thus, they and their families/carers may need access to a complex combination of different services across a number of different settings. These settings can include hospital, community, care home, sheltered/extra care housing or hospices and, on some occasions, end of life care will also be needed in other locations such as prisons and hostels for the homeless. The particular needs of those with reduced capability for decision-making also need to be considered, such as people with dementia or those with severe learning disabilities and mental health issues. Irrespective of who the person is, where they are and whether this is a place of their choosing, the same principles and standards of good end of life care apply.

The book discusses many of the actions needed for service improvement and identifies some of the resources available to improve the quality of services and, including the socioeconomic, cultural factors and religious and spiritual traditions that need to be taken into account when designing and undertaking service improvements. These all add to the perception of a quality experience and higher satisfaction levels for the individual and their families, as well as giving greater satisfaction to staff delivering the service by knowing they are supporting the individual in the most appropriate way. For the individual and their families to experience a seamless, high quality of care experience generating high levels of satisfaction, services need to be delivered through integrated person-centered end of life care between organisations and across sectors. This challenge for quality end of life care becomes particularly important as the person's needs intensify and become more complex as the person progresses through the final stages of life.

Conclusion

The volume identifies four themes/principles that remain critical to contemporary end of life care: valuing the uniqueness of the individual experience; the principle of holistic care; promoting a culture of openness and understanding the end of life as a journey that ends in death. Taken together, these principles underpin the notion of the 'good death', or 'dying well', discussed in detail within Chapter 6 of the book and recently highlighted by the Department of Health and Age Concern. Achieving a good death is now seen as both a social and political priority. The focus on choice and ensuring that people are supported to die within the place of their choosing wherever possible is emphasised. Good communication underpins all aspects of co-ordinated, integrated and seamless end of life care. Communication needs to be across professionals, organisations and agencies, but most importantly with individuals and their families so that their wishes and preferences can be met where clinically viable. Sharing of information about an individual to enable services to work together must be with the individual's consent and this is at the heart of achieving a successful, co-ordinated experience of care. However, underpinning all the strategies, tools and mechanisms for achieving co-ordinated end of life care must be the commitment from all organisations and agencies to work together across boundaries in the best interests of the person at the end of life. By focusing on specific chapters the book could be used for training health and social care staff. The authors have achieved their goal by providing some 'food for thought'. They have explained how good care in the dying phase requires excellent communication and assessment skills, planning, co-ordination of care underpinned by knowledge, compassion and sensitivity.

Despite the fact that only six contributors wrote this text, they all speak with one voice as they have all previously worked together on the National End of Life Care Programme UK and continue working in this speciality in central government and university positions. They acknowledge: "It is a privilege, the final opportunity professionals and carers have to ensure that this unique person leaves the world peacefully and with dignity." If some programme could be designed to keep essential

books in care of the elderly wards in hospital and residential care homes, with staff encouraged to discuss them, then "Pathways through Care at the End of Life; A Guide to person-Centred Care" should be among such books. Having access to carefully defined good practice in the emotionally demanding work of caring for people at the end of their life is essential. In this context, the current volume is highly recommended.

Conflicts of Interest

The author reports no conflicts of interest.