Access to Palliative Care

Tony Ryan

Abstract
Access to palliative services is currently an important issue facing policy makers around the globe. Much of this discussion is centred upon the significant challenges facing the developing nations and how health care leaders are seeking to integrate high quality palliative care. But inequality of access is also apparent within developed health care economies. This chapter addresses some of these challenges as they are experienced by those suffering from non-malignant conditions. Using two case-studies the chapter highlights evidence that draws attention to the ways in which people with dementia and those experiencing Chronic Obstructive Pulmonary Disorder (COPD) are often excluded from palliative provision.

1 Introduction

The World Health Organization now regards access to palliative and supportive care at the end of life as a human rights (World Health Organization 2014). While much has happened in policy terms to facilitate the development of such services, particularly in developed nations, the reality for many means that they will experience an end of life where access to palliative care is
denied (Brennan 2007). Evidence from the UK suggests that every year over 100,000 people who demonstrate high levels of palliative need will die without the benefit of such care, and poor access continues to be experienced by particular groups of patients via persistent inequalities (Dixon et al. 2015). In the past, inequity has been demonstrated as a result of socioeconomic status (Lewis et al. 2011), while others have noted inequality of access to palliative care on the grounds of sexual orientation (Harding et al. 2012) and age (Gardiner et al. 2013). However, a key theme of much of the literature relating to inequality of access to palliative care focuses on the importance of the patient’s condition. The experience of cancer patients has for some time, at least within developed healthcare systems, continually demonstrated elevated palliative service usage and improved outcomes for those diagnosed with a form of cancer (Boland and Johnson 2013). In contrast, nonmalignant conditions have been the subject of relatively slow progress and poor access. For example, US citizens living with nonmalignant chronic lung disease are less likely to access palliative services (Brown et al. 2016). Similarly, people suffering from heart failure also demonstrate poor access to palliative care (Gadoud et al. 2013). Readers of this book will be well aware of what we mean when talking about such care, but how this is accessed or indeed denied and what shape or form palliative care takes is not so clear cut. This chapter will explore the literature which centers upon access to palliative care. It will explore what we mean by access via the more contested notion of transition. Furthermore, the chapter will look at inequity of access across the globe and across particular condition groups. Using two case “exemplars,” the chapter addresses sources of barriers to access and attempts to provide a way forward in policy and practice fields.

2 Palliative Care: Access to What?

Across the globe, a great variety of forms of palliative care exists. Wiencek and Coyne (2014) point to four models: ambulatory; home-based; hospital-based specialist units; hospital-based specialist services (consultation). A global perspective of the scope and reach of palliative care services suggests that, although patchy, the pervasiveness of such provisions is increasing (Lynch et al. 2013). Add to this the growing potential for palliative and supportive care to be provided in residential and nursing home facilities for older people and a fairly complex web of services and types of provision exists. Measuring access to specialist palliative care services, such as those listed, provides a relatively straightforward means to exploring patterns of service usage across and within populations. In doing so, we are able to observe patterns of service usage, inequalities, and unmet need. But measuring how patients access palliative regimes of care is less straightforward. Kaufman (2015) talks of the process of crossing a threshold at the end of life when care turns from a curative form to palliative, readers will also be familiar with wedge and wave models of shifting approaches to the care of patients. The notion of transition has emerged as an important notion in the process of these changes in the emphasis of care and treatment. Two reviews looking at the nature of transition from curative to palliative care have been undertaken in the past (Gardiner et al. 2011; Marsella 2009). Both reviews point to the importance of understanding the nature of transition, partly as a result of the relationship between the introduction of palliative care and outcomes for patients. But addressing transition is important because of the increasing focus upon inequality of access and the attention that this brings to the investigation of barriers to palliative care experiences. Those writing about transition have noted that it is often not clear cut, particularly in the absence of a specific referral or physical admission to a specialist service. In other words, transitions can often occur while patients remain within the same place of care, such as a hospital or ward setting, often under the treatment of the same team of clinicians. This is partly an outcome of more recent approaches to palliative care, which firstly may be undertaken by generalist staff, but secondly as a result of the use of curative approaches which coexist with palliative care. The timing of
transition is of critical concern to those undertaking research in the field, but more importantly to the medical and nursing staff providing care, patients, and their families. One of the key challenges remains the culture and environment of care where transitions are experienced. Kaufman (2015) in her classic ethnography of end of life care on the United States points to this as one of the key challenges in making the transition, and something we will return to later in this chapter. But equally challenging remains the issue of prognostication. As increasingly experience death as a result of noncommunicable disease and long-term chronic conditions, the nature of end of life trajectories has shifted toward protracted and unpredictable clinical states thee ways in which medicine can prognosticate effectively (Murray et al. 2005).

Notwithstanding the problems associated with observing and measuring its prevalence, there remains a great deal of evidence to suggest that there exists inequality in relation to the experience of accessing services and making the transition to palliative and supportive care is problematic for some groups of people. This chapter will use two case exemplars to highlight such inequality.

2.1 Case Exemplar One: Dementia and Failure to Make Transition

There are almost 40 million people living with dementia across the world (Prince et al. 2013). Recent global policy has placed emphasis upon early diagnosis, better information and support, as well as enhanced end-of-life care throughout the condition trajectory. Indeed the improvement of access to palliative care and high quality end of life care has become an important policy objective across the globe. Palliative care and improved end of life experiences for people with dementia is emerging as a critical area of concern and debate, with national dementia strategies across the globe focusing attention upon the issue of access (Nakanishi et al. 2015).

The evidence to support claims that people with dementia do not access palliative and supportive care comes from a range of sources. For a long time, access to hospices was more or less denied to people with dementia, with less than 1% of the hospice population of Europe being diagnosed with a neurological condition (Sampson 2010). This failure to access a key front line palliative care service having implications for referral to other specialist end of life services. Recent research undertaken in the UK would further support these observations. Based upon census research carried out within two large hospitals, identifying the range and prevalence of symptoms which might indicate palliative needs (Gardiner et al. 2013), people with dementia were identified as experiencing heightened levels of physical burden (pain, fatigue, poor function) and psychological burden (anxiety, depression, mood) when compared to other patient groups, such as those with cancer. Despite this heightened degree of burden, people with dementia were less likely to have made the transition to palliative forms of care, especially in the form of a referral to specialist services (Ryan et al. 2013). Furthermore, a number of reviews have highlighted the lack of transition to more palliative forms of care for people with dementia at the end of life, with the continued use of regimes of care which favor an aggressive approach. Paradoxically, it is claimed that throughout their illness people with dementia often receive “too little” care, whereas end of life care is often characterized by “too much” (Small et al. 2007). A failure to access palliative care for people with dementia has, it might be argued, led to poor quality end of life experiences. In the past, a tendency to rely upon aggressive forms of medical care (feeding tubes for example) have been emphasized, denying people with dementia the opportunity for more palliative approaches at the end of life, with little or no evidence suggesting this form of care contributed to improved outcome (Sampson et al. 2009). More recently evidence from the Netherlands has highlighted similar unequal access to palliative approaches to end of life care. For a long time, the systematic use of antibiotics has been viewed as a means of extending life, often at the cost of quality of life. Hendriks et al. (2015) identified increased prevalence their use among people with dementia, when compared to cancer patients. There is also
continued evidence that enteral tube feeding is more prevalent amongst hospital patients with dementia at the end of life, a practice which might be considered contrary to palliative principles.

2.2 Case Exemplar Two: Chronic Obstructive Pulmonary Disease (COPD)

COPD is the umbrella term given to represent a range of chronic lung disease, including emphysema, chronic bronchitis, and chronic asthma. It is characterized by increasing chronic breathlessness. There are estimated to be around 380 million people living with COPD worldwide (Adeloye et al. 2015). As is the case with dementia, the end of life care experience for people with COPD continues to be blighted by unequal access to palliative services. Furthermore, there is evidence that patients with COPD often fail to make the transition to palliative regimes of care, especially compared to other conditions. A recent major US study highlighted a lack of access to palliative care for patients with COPD after hospitalization (Rush et al. 2017), noting unfavorable comparisons with patients with cancer. Szekendi et al. (2016), also reporting research carried out in the US, observed high levels of unmet palliative care need and identified COPD patients as being less likely to be referred to such services. Furthermore, Ahmadi et al. (2015) identified a reduced proportion of patients with COPD receiving a referral to palliative services (including home-based), increased hospital admission, and few opportunities for end of life discussions.

As is the case in dementia, there is also evidence that, use of specialist services aside, people with COPD also fail to make appropriate transitions to high quality end of life care when compared to other patient groups. The Ahmadi et al. study (2015) is also interesting in this respect. The team was able to collect data on symptoms at the end of life, noting higher levels of uncontrolled breathlessness, nausea, and confusion at the end of life for COPD patients, when compared with cancer patients at a similar point in the disease trajectory. Invasive procedures are also likely to persist within the end stage COPD population, with mechanical ventilation being difficult to withdraw once established and indicating a high level of burden on the patient and family (Hajizadeh et al. 2015). One important element of palliative and end of life care is to have open discussions with those caring for the person. A great deal of the literature within the field of COPD and palliative care relates to this issue, with some evidence that the opportunities for discussion are limited for COPD patients, again when compared to those with cancer (Rocker et al. 2008).

3 Explanations for Inequity of Access

The reasons for this inequality of access for people experiencing dementia and or COPD and reluctance for providers to facilitate transition are now well established and barriers to palliative care for people with dementia are known to take a number of forms.

3.1 Prognostication

Note has already been made within this chapter about the nature of the end of life experience for people suffering from long-term chronic conditions. The implication for transitions to palliative forms of care is centered on the timing of changes in treatment or indeed the decisions to refer to a specialist service. Some argue that the failure to prognosticate effectively is, however, a product of a culture of care which is more readily focused upon life sustaining treatment as opposed to palliative care. Coupled with a rise in the use of life sustaining technologies, prognostication is increasingly delayed (Seymour and Gott 2011). Nonetheless, prognostication is difficult within the context of dementia and several authors have therefore chosen to cite this issue as a particular reason for this failure (Birch and Draper 2008). Typically a person with dementia will live for around 5 years after diagnosis, but this varies and the trajectory of experience is unique to each person. This is made more complex when the
person experiences comorbidities or death as a result of an additional condition (Lee and Chodosh 2009). Similarly, prognostication in the context of COPD is problematic, leading to challenges in transition to palliative forms of care.

Despite the challenges in the field of prognostication in dementia, some attempts have been made to identify markers which might be indicative of the last 6 months of life. Van der Steen et al. (2014) argue that professionals should be able to use clinical judgement alongside such tools to help in the process. Importantly, they add that communication with the family on the issue of prognostication is critical to help in the preparation of shared decisions making. Efforts to develop prognostication tools within the field of COPD have similarly taken place. The PROLONG tool uses 11 indicators to assess mortality postdischarge and has shown promise within early field trials (Duenk et al. 2017).

3.2 End of Life or Advance Care Planning Discussions

Open discussion about end of life treatment is thought to enhance decision making and provide preferential regimes of care in the late stage chronic conditions. The most prominent form of discussion is termed Advance Care Planning (ACP), defined by the World Health Organization as: “planning in advance for decisions that may have to be made prior to incapability or at the end of life. People may choose to do this planning formally, by means of advance directives, or informally, through discussions with family members, friends and health care and social service providers, or a combination of both methods” (World Health Organization 2004). ACP is felt to improve end of life outcomes for people experiencing a range of conditions (Brinkman-Stoppelenburg et al. 2014). In both dementia and COPD contexts, however, the prevalence of active engagement with ACP is thought to be low (Lovell and Yates 2014) and a number of explanations have been put forward. In the context of dementia, it is thought that the idea of planning for the end of one’s life is both actively and passively avoided. A recent review of the qualitative literature on the subject suggests a number of explanations which alongside avoidance of the matter include: lack of support from services; carer burden; living for today; a lack of confidence in professionals being able to deliver choice (Ryan 2017). In the case of COPD, a similar line of exploration has taken place. Patel et al. (2012) note that patients lack an awareness of ACP options, they do not have well established lines of communication with professionals, fear of abandonment, and an assumption that conversations will occur when they are needed. Additionally, the authors note delays in diagnosis and concerns among physicians that initiating ACP will take away the patient’s hope.

It is difficult to assess the significance of the absence of ACP on the quality of end of life care or transition to preferred forms of palliative care. Nonetheless some suggestions are provided to help facilitate the ACP process within both a dementia and COPD context. Ryan suggests that the skills within professional groups need to be enhanced so that initiation of future planning conversations may take place (Ryan 2017). Furthermore, the importance of sharing the responsibility of planning is stressed to help lift the burden of responsibility from the individual and family. Patel et al. (2012) also stress the skills involved are complex and subtle, pointing to the importance of appropriate timing of the conversation and relaxed environment. They also highlight the evidence relating to decisions aids as a potential route to improved prevalence of ACP within the COPD population.

3.3 Organizations and Cultural Factors

Kaufman’s classic ethnography of US hospitals focuses very much on the environmental and cultural features of institutions and professional groups in their influence on end of life care (Kaufman 2015). This study is important as it helps us to gain insight into the values, concerns, financial, and policy drivers which shape decision making. She notes a great deal, but among these valuable insights, Kaufman highlights the ways in which
discussion about death is delayed, partly as a product of the medical profession’s attention to life sustaining treatments and a failure to see it as a possibility. The literature around the failure of people with dementia or COPD to gain access to palliative care via transitions or the accessing of services rings true here. Within both conditions, there is a reluctance to view end of life as a possibility. In a paper which engaged the views of medical and nursing staff about access to palliative care services for people with dementia, the notion of candidacy is used (Ryan et al. 2012). This describes the idea that dementia is not viewed as a cause of death and as such people with the condition are not viewed as candidates for palliative services.

The nature of the exploration of end of life care for people with dementia in the book by Small et al. (2007) chimes also with Kaufman’s work. This study focuses on what is called the distinction between the “life world” of the person, their sense of self, wishes, and preferences and the “system world” a culture of care which denies preference, choice, and autonomy, consequently leading to overuse of technology and life sustaining interventions. Organizational issues have also been identified as a barrier to the accessing of palliative services, particularly in the form of generalist provision in the field of COPD. Hynes et al. (2015) working in acute environments in Ireland draw attention to the episodic nature of hospital care which focus on the short term management of exacerbations. This, they argue, is at odds with a long-term approach to understanding the physical, emotional, and spiritual challenges faced by people with long-term conditions such as COPD. Specifically, they state that rather than a person-centered approach, acute environments address these challenges with a “disease-centered” focus.

3.4 Systems and Resources

Many have noted the problems faced by people with dementia or COPD in relation to access to palliative services or end of life care as a result of systemic failings or resource limitations. Recent research in the United States demonstrates relatively poor access to hospice care for patients diagnosed with COPD and neurodegenerative disorders when compared with cancer patients (Riggs et al. 2016). Problems in gaining access to services such as hospices in the field of COPD are also noted. Vermlyn et al. (2015) describe access problems in the UK as a result of hospices being viewed as a resource for cancer patients. In the USA, the issue of access to hospice care is made more complex by Medicare regulations, with eligibility restricted to those in the last 6 months of life and who forgo curative treatment resourced via Medicare (Part A) funding. Given the problems associated with prognostication for people with COPD or dementia, it is not difficult to see how these access problems may persist. Referral and communication issues of a systemic nature have also been shown to restrict access for particular groups of patients, including those diagnosed with dementia. Illife et al. (2013) have conducted pan-European research to highlight the problems associated with a failure of community-based medical practitioners in identifying people with dementia as candidates for specialist services, noting that in some cases fewer than one in five were recorded on palliative care registers.

Palliative provision outside of specialist services is often undertaken by generalist staff working either in community- or hospital-based settings. For some time now, the challenges in generalist staff being able to provide palliative forms of care have been noted, especially in acute settings. Gott et al. (2012) note in their work in hospitals that resources were often identified as the reason that generalist staff were unable to provide what they saw as high quality palliative care. Specific examples from the field of COPD highlight this issue. During fieldwork, Hynes et al. (2015) note that COPD specialist nurses in Ireland were being expected to carry significantly higher workloads when compare to specialist palliative practitioners within the same organization. Ryan et al. (2012) note that specialist palliative care providers often viewed eligibility for access to hospices as being limited to those diagnosed with cancer. In particular, they report already stretched resources and limited capacity in
dealing with the specific needs of people with dementia as a means of rationing access.

## 4 Implications for Future Policy and Practice

This chapter has highlighted the inequity which is evident in accessing palliative care for two specific populations of patients: people with dementia and those diagnosed with COPD. This is not to say that inequality does not occur for other patient populations or indeed along other lines, such as socioeconomic or between developed and developing nations. Rather the two case studies used here exemplify condition specific inequality and the sources of inequity. A number of potential explanations have been offered and it now may be pertinent to offer a way forward. Firstly, specific guidance should be made available where problems of access or palliative care practice deficits are identified. This has already occurred in the case of dementia to some extent. The EAPC White Paper on optimal care for older people with dementia has helped to clarify consensus on this issue in a European context (van der Steen et al. 2014). A number of key features were identified, including access to palliative care, promotion of advance care planning, avoidance of overly aggressive approaches at the end of life, and education and training for key health and social care professionals. Guidelines do, however, need to be developed to meet the needs of national populations and embedded within organizational practices and cultures of care. Secondly, a critical perspective around the relative importance placed upon prognostication is required. It is well established that prognostication is challenging within the context of some conditions. But prognostication is only relevant to end of life decision making. Palliation is much broader than end of life care and needs to be embedded within pathways of care from a much earlier time point. Placing less emphasis on prognostication and more on the introduction of the palliative principles of care would allow for the introduction of such approaches in a timely and appropriate manner and would have the benefit of improving end of life experiences. Thirdly, it is clear that established methodology around ACP is failing populations of people who suffer from long-term chronic conditions. Work is required in enabling more informal approaches to ACP to be established, where a focus on relational practices and collective responsibilities are central themes. Health and social care professionals need to be provided with the capacity (skills and resources) to be able to introduce the notion of ACP at a timely manner for all.

## 5 Conclusion

This chapter has drawn attention to some of the key challenges facing policy makers and practitioners in addressing some of the inequalities in palliative care provision. Using two distinct case studies, the chapter demonstrates that while access to palliative care in developed countries remains relatively unproblematic for some patients, especially those with malignant disorders, the route for others is more fraught. A number of explanations are considered and these have implications for professional groupings, policy makers, organizational leaders, and legislative bodies. Evidence surrounding the issue of inequality in the developed world remains insubstantial compared to those global concerns about access to palliative care for all. If access for all is to be realized and the goal of palliative care as a human right is to be achieved, then there remains a great deal of work to be done.

### References


Hendriks SA, Smalbrugge M, Galindo-Garre F, Hertogh CM, van der Steen JT. From admission to death: prevalence and course of pain, agitation, and shortness of breath, and treatment of these symptoms in nursing home residents with dementia. J Am Med Dir Assoc. 2015;16(6):475–81.


