

Care and compassion at the end of life

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Abstract

Aim: To examine the provision of the 'end of life care strategy' and the perception of provision by patients and carers. Introduction: In determining what constitutes excellence in care at the end of life, one must firstly acknowledge 'what care and compassion is'. Following this it should be established what one should expect as a minimum standard of care. The end of life care strategy was initiated by the Department of Health in 2008. This guidance was intended to drive forward end of life care provision where patients were seen as the priority and encouraged to engage in all decision making at each point in their journey. Standards suggested by NICE (2011) further support patient empowerment and inclusivity in care planning.

Method: A literature search was conducted in order to determine whether there has been a change in provision and to identify whether patients and their carers perceive an excellence in the care that has been delivered.

Results: The literature is limited but the underlying issues of pre-end of life care strategy (2008) remain apparent. Patients and their carers continue to lack the autonomy they deserve and decisions are made about them rather than by them. Owing to the lack of direction which

should come from the patient, care may be fragmented with numerous members of a multidisciplinary team being involved.

Conclusion: Patient involvement is paramount. Early discussions relating to choices at the end of life need to be achieved in a timely manner. This should ensure that the patient and carer experience a high standard of excellent care which has been planned with inclusivity in mind

Keywords: Care provision, compassion, excellence, end of life

“You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but to live until you die” (Saunders 1976).

This profound statement was a pivotal moment and helped to shape palliative care provision. It suggested an ethos and philosophy of care that was needed for those reaching the end of life. What needs to be determined is how can healthcare professionals achieve this goal for all patients and, if this is achieved, does it ensure a compassionate approach to care?

Historically, palliative care provision had been a low priority. This resulted in a deficit in knowledge base amongst many healthcare professionals through inadequate education provision. The consequences suggested suboptimal care for many patient's (Department of Health (DH) 2008). This not only effected the patients quality of life but also, potentially, that of their carer's and one may argue, the staff caring for the patients as frustration regarding service provision may lead to low morale.

Each year half a million people die in the UK, with two thirds being over 75 years old. The National Audit Office (2008) determined that the majority of palliative care provision is provided for the younger patient indicating that there may be an element of inequity. In view of the ever increasing aging population and the recognition that palliative care provision should be available to all patients no matter what their diagnosis, socioeconomic status or geographical location, what needs to be determined is, how do we provide high quality, compassionate palliative care to all who need it? The DH (2008) and the National Institute of Health and Clinical Excellence (NICE) (2004) have issued strategies and guidance in order to ensure access for all and service provision should be evidence based with a clear minimum standard identified. In addition, improved communication strategies and more collaborative working should be encompassed in order to facilitate high quality end of life care. Despite calls to ensure the facilitation of patients preferred place of care, there still remains a large proportion of end of life care delivered in the hospital environment (NAO 2008). As healthcare providers, one should ensure that staff providing care are equipped with the knowledge and skills required in an environment that may not be the patients first choice for reasons that may be irresolvable before their death.

This discussion will focus on healthcare provision and the support and training needed from a nursing care perspective.

How does strategy affect practice?

Since the publication of the National Cancer plan (DH 2000) the National Health Service (NHS) has seen a proliferation in policies and standards

surrounding the care of patients, not only with cancer, but also a recognition that those with life limiting conditions deserve access to high quality end of life care (DH 2008, DH 2009, NICE 2004, NICE 2011, NICE 2012). The guidance has common themes which include recognition of the importance of clear communication between all the members of the multi-disciplinary team. In addition clear communication with the patient and their carer ensuring they are empowered and inclusive in their care planning and decision making.

Both extrinsic and intrinsic influences may affect or influence the patient's journey e.g. the provision of services and resources, previous experiences, support mechanisms and the relationships and trust fostered by those caring for both the patient and their carer. These influences may have a positive effect but also may negatively affect their quality of care during what may essentially be, the last days of a patient's life and the ongoing bereavement experienced by their carer's and loved ones. It is vital that the healthcare professional is cognisant of all the pertinent issues by undertaking a comprehensive and accurate holistic assessment. A continuous approach to assessment should be fostered as issues and experiences are often dynamic processes which require a responsive, compassionate and caring attitude in order to ensure the patient and their carer feels valued and supported.

The holistic assessment should encompass multifaceted aspects of the individual's experience including the:

- Physical
- Social

- Psychological
- Emotional
- Spiritual

(NICE 2004)

An evidence based approach should be adopted in an effort to deal with the patients and/or carers concerns in a collaborative manner, i.e. the patient should prioritise the problem areas or symptom issues. Both the DH (2008) and NICE (2004) advocated an investment in staff providing this service was paramount. This investment would hopefully address educational needs and by addressing these needs create a new depth in understanding from those undertaking such intimate and essential care.

It is acknowledged that Macmillan, Marie Curie and Specialist Palliative care teams are associated with high quality care of the dying. As a result of resource issues very few individuals in the last days of life have access to these professional groups. The Palliative Care Team in the Royal Liverpool Hospital had contact with only 15% of the patients who died in the study period they examined (Kinder & Ellershaw 2003). Nationally 66% of deaths occur in hospital (NAO 2008) therefore, it is essential that healthcare professionals in the hospital environment are adequately prepared for this difficult role. There are countless teams of healthcare professionals who provide excellent end of life care but there are teams who have high caseloads and stretched resources therefore delivering the care required and ensuring they receive the investment in their ongoing education surrounding end of life care may be inherently difficult. The

elements of care which may be low from a priority perspective are the emotional aspects as these may be seen as time consuming and difficult to measure the effectiveness of their interventions. Dealing with a patients' pain and nausea is a measurable component but addressing a patients anxiety and emotional distress is difficult to quantify in terms of effectiveness. This may be identified in a study by Skilbeck et al (2002) 57% of the 814 referrals to the palliative care team within an acute hospital trust were for emotional support. It may be reasonable to suggest that many of these referrals could be managed using the expertise of the healthcare professional already caring for them. One reason for referring to the palliative care team may be the feeling of inadequacy and lack of preparedness for this intimate role. What is evident however is that a uniform approach to end of life care should be adopted and listening, informing, referring to other members of the multidisciplinary team when appropriate can all aid the best possible quality of life and facilitate a compassionate approach to end of life care.

End of life care is already a distressing experience, patients may undoubtedly feel anxious for obvious reasons, relatives and carers may be dealing with their loss even before the patients' demise. Staff may also feel distress due to the experience of caring for patients at the end of life particularly if they do not feel prepared educationally or emotionally. To prevent a more distressing experience for all involved, staff need to be aware of the resources available and the current evidence, including any policies or frameworks to inform and/or regulate their practice and to some extent, that of others. Without this understanding and awareness

patients, carers and healthcare professional may be subjected to an altogether more negative experience.

The role of the healthcare team involved in care at the end of life should be to provide relief from pain and other distressing symptoms. This may be achieved by rationalising the causes of symptoms, treating the treatable and utilising the best available therapies in order to maximise the patients quality of life from diagnosis to the end of life. Pathways have been acknowledged as key in optimising baseline standards of care (NICE 2004). Effective symptom management is synonymous with quality care at the end of life. NICE (2012) have addressed both these aspects in the introduction of guidance surrounding pain relief in end of life care which is aimed at all end of life care irrespective of diagnosis. As with all symptom management, selecting the appropriate drug, titrating it effectively whilst acknowledging the effect co-morbidities could have on the pharmacodynamic aspects of the drug is paramount for patient safety. Effective pain relief is fundamental in end of life care to ensure dignity in death and healthcare professional's knowledge and understanding is vital. What one has to be mindful of is that end of life care should not hasten nor postpone death but should deal with symptoms in an ethical manner often weighing up harm versus benefits of treatment and affirm life and living but not at the expense of quality of life (National Council for Hospices and Palliative Care Services 2001).

In addition to symptom management health and social care professionals should offer a support system to help patients live as actively as possible until death and this should extend beyond the patient to the family and/or

carers during the patients' illness and in their own bereavement. With this approach, a hope is fostered by all involved which may facilitate a new-found freedom and acceptance giving the patient and carers space and time (hopefully) to reflect and plan (Bradshaw 1996).

Health and social care professionals need to be mindful of what their role is in the care of the patient at the end of life. It should incorporate an understanding surrounding who they are supporting, who they are caring for, who they are working with and have access to extra support should this be necessary. In addition, ascertaining available information and recognising what extra information may be necessitous in order to care for this person and their carers or relatives in a holistic, compassionate manner. What is paramount and is reiterated in end of life and supportive care strategies is the requirement that the care that people approaching the end of life receive is aligned to their needs and preferences (DH 2008, NICE 2004).

The goals for the future are to ensure that individuals reaching the end of life spend an increased length of time in their preferred place of care.

From the research conducted by the National End of Life Intelligence Network (2010), age of the patient, their terminal condition and social circumstances may be more predictive regarding the opportunity to die in their preferred place than previously recognised. This has huge connotations when the goal in end of life care is access to all, equity and empowerment. What is evident in the research and highlighted in this discussion is that patients' wishes should be met where practicable, but it should be emphasised that this is not always practicable. Safety of the

patient, carer and staff should be paramount when considering the most appropriate and desirable environment in which to deliver end of life care. Issues preventing care being delivered in a specific location may be, for example, the potential for complications as death approaches or resource issues. This does not excuse the lack of forethought regarding anticipatory problems e.g. requirement for different methods of medication delivery or treatment of anticipated seizures. This proactive approach may help to reduce unscheduled care or hospital admissions leading to death in hospital (where death in hospital is against their stated preference) and the reduction in deaths in inappropriate places such as on a trolley in hospital or in transit in an ambulance. NICE (2004) suggest that reasons for issues such as these may be lack of anticipatory planning and this may be due to inadequate preparation for the role and lack of understanding and knowledge surrounding symptom management at the end of life. One may argue that this can have a detrimental effect on the patient and carers end of life experience and subsequent quality of life.

Carers are a valuable part of care delivery in this country and valuing and supporting them with a compassionate philosophy is recognised as a key feature for strategies and management of patients with life limiting illness nursed in the community. The National Cancer Survivorship Initiative (NCSI) is a specialist team working in an attempt to improve care and the quality of the care delivered to patients and their families by recruitment of communities and piloting various care strategies and models in attempt to inform future practice (DH 2010)

NICE support their standards through ongoing research, it is paramount that research is undertaken in the field of end of life care. In their publication in 2004, there was a call for further research examining patient perceptions and priorities for end of life care but in addition patient and carer experience in end of life care provision. The National End of Life Care Intelligence Network is examining all life limiting illness and aims to address these issues alongside the examination of palliative care provision throughout the UK and the accessibility to multiple social, economic and cultural groups. The Network should improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector, to adults approaching the end of life. This intelligence may help to drive improvements in the quality and productivity of services.

A Cancer Improvement team have been initiated to work with service providers in critically examining service provision within their area, but in addition financial savings are on the agenda. The consultation should involve an inter-disciplinary team and user groups to inform and encourage innovation and improve service provision whilst also ensuring value for money in this difficult financial climate. With such ambitious targets one may question the reality of not only making such savings but with the additional aim of improving patient experience.

What is evident is that further investment in staff is required; more research needed and greater understanding and compassion essential from those endeavouring to deliver high quality services to individuals reaching the end of life. Unfortunately education provision comes at a

cost. One may argue however that if care provision is more focused and informed, effective treatment regimes, prescribing and anticipatory treatment should improve the efficiency and effectiveness of service delivery therefore leading to a more supportive and responsive service for the patient and their carer. For good practice to be considered the norm, rather than the exception then education and training supported by policy provision is essential. A recognised mechanism for dissemination of good practice is also required for innovation in end of life care.

This discussion has highlighted the need for education and support to staff providing end of life care. The aim is to ensure patients are empowered and feel staff providing their care are responsive to their needs. Whilst the aim is to provide care in the patients preferred place one needs to recognise that this is where practicable, investment is needed in all staff no matter what profession or place of care provision. Policy aims to ensure provision of care is effective, responsive and is an economical use of limited resources. Further staff development and support may be the only means of carrying these goals forward. With evidence suggesting an increasing ageing population who are reported to be the largest consumers of healthcare resources (DH 2001, NAO 2008), greater demands on services may be encountered and the effective means of managing symptoms will be essential for those reaching the end of life.

But how does all this facilitate compassion at the end of life? If we have an understanding of patient priorities, palliative care provision can be shaped utilising a responsive approach by examining patient needs and priorities.

This will allow providers to focus on essential care delivery requirements without compromising quality in end of life care at a time when resources are constrained and efficiency and effectiveness are fundamental to service provision.

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