

The Development of Supportive Care for Cancer Patients in India: A UK Perspective

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Abstract This article discusses the development of supportive care for cancer patients in India from a UK professional nursing perspective.

Keywords Cancer treatment · Advanced nursing roles · Palliative care · Advance care planning · End of life care

Introduction

Decision making in surgical oncology no longer lies within the remit of the individual clinician. The multidisciplinary medical team is the modern vehicle by which evidence based treatment is focussed on the individual cancer patient, and by which the professional duties of each member of the clinical team are brought to bear to the patient's benefit.

The patient's cancer journey begins with recognition of the need to seek help and advice for a particular set of symptoms and signs, or discovery through a screening programme. In advanced health economies, the first point of professional contact will usually be a primary health care facility, general or family care practice, staffed by medically qualified general practitioners and primary care nurses. In rural India, access to conventional and professionally qualified medical care may be significantly delayed by alternative practitioners and by uninformed advice.

Once the patient reaches hospital, he or she will come under the care of the wider multidisciplinary team. This will include a wide range of allied health care professionals, including nurses, physiotherapists, radiographers, specialist and laboratory technicians, clerical, administrative and ancillary staff. Among these professional groups, empowerment of the nursing profession offers perhaps the greatest potential for immediate gains in productivity in cancer care, and in improving the patient's experience along the cancer journey.

Advanced Nursing Roles

Over the past two decades, the UK has seen a very significant shift to enhanced roles for nurses along the cancer pathway, and a shift of labour intensive and task orientated roles such as ward cleaning and meal distribution to auxiliary staff. Drivers to this change have been varied and supported at national level by the Department of Health (DH) to modernise nursing careers [1]. They have included:

- Government led demands for the nursing profession to take greater clinical responsibility e.g. legislative changes allowing nurses independent prescribing
- The gradual transition of nursing to an all-graduate profession
- The shortening of the junior doctor's working week to around 48 h, in compliance with European Working Time directives, and the consequent need to distribute a junior doctor's past duties such as phlebotomy and surgical assistance to other staff
- The relative costs of nursing and medical staff to undertake standard and defined tasks.

The process of transition has nevertheless challenged many assumptions among doctors and nurses about their role and responsibilities.

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In consequence a wide range of specialist nursing roles have evolved, and the process is almost certainly incomplete. Such roles have included:

- Specialist cancer nurses (e.g. breast, colorectal, head and neck) who act as the primary interface between the hospital service, cancer specialists and individual patients; as patients' supporters and advocates during the cancer journey; and as enablers to help patients access particular services and information:
- Pre-operative assessment nurses, who are trained in interpreting a set of diagnostics in a surgical pre-assessment clinic to make a decision about whether someone is fit for surgery
- Surgical Practitioners (Oncology), Anaesthetic Practitioners and Surgical Assistants within the Operating Theatre (OT), alongside conventional OT roles:
- Nurse Prescribers, Nurse Practitioners and Advanced Nursing Practitioners on the Wards and in Primary Care, who could be undertaking such roles as administering treatments such as chemotherapy:
- Mental health practitioners, Social Services nurses, Generic health care workers and End of Life Care Educators (EoLCE), to name just a few specialities.

Competence and Accountability

The UK Nursing and Midwifery Council (NMC) is a professional regulatory body and exists to safeguard the health and wellbeing of the public. The NMC recognises that nurses undertaking cancer care duties must have the appropriate competence for their role and work within a clear chain of accountability. They are themselves accountable for their actions once responsibility has been appropriately delegated. In 2008, the UK NMC directed [2] that:

- Practitioners must have the knowledge and skills for safe and effective practice to work within legal boundaries;
- Practitioners must recognise and work within the limits of their competence and patient expectation;
- Each professional is personally accountable for their actions and omissions and must always be able to justify their decisions.

This is summarised in the personal direction to relevant professionals that:

You are professionally accountable for your practice: answerable for your actions and omissions, regardless of advice or directions from another professional

Such delegation of authority is made on an individual basis. Competency implies that the individual must have the appropriate core skills, education and additional training; the

knowledge needed to judge the appropriateness of their actions and practice in their allocated role; and the willingness to do so.

It also places a duty of care and responsibility upon the employer to ensure that the training is delivered and properly assessed. Once trained, the nurse will then accept responsibility and accountability in those specific duties towards the patient; towards the doctors charged with the care of that patient; towards the employer or health care delivery unit; and towards the Professional, State and National Regulatory Authorities, such as the UK NMC.

Such a system clearly cannot be established overnight if it is to protect all parties in the transaction, and primarily the patients themselves. It implies an attitudinal shift at all levels, as in

- the medical profession, to recognise the significance and importance of the process, and to support the necessary changes;
- The nursing profession, to want to accept the changing roles and increased professional responsibility;
- The educators, including the schools of nursing and (increasingly) the higher educational establishments and universities which will move towards undergraduate and post graduate nursing programmes;
- The employers, providing the workplace procedures, training opportunities and structures of accountability in which advanced nursing practice can evolve;
- The national professional regulatory bodies, such as the NMC in the UK
- The State and National legislative bodies, who create the permissive environment and the funding streams within which such changes can take place.

We hope to return to some of these issues in greater detail in future articles. In this article, we wish to focus particularly upon the issue of Supportive and Palliative Cancer Care Services, and the role of nurses in the care of patients whose disease and its treatment creates physical and emotional morbidity and social dislocation, and whose disease progression produces a range of unpleasant symptoms and consequences which must be addressed.

Empowering Health Workers in Palliative Cancer Care

Cancer being the disease that it is, many patients will not be cured of the disease. They will return to their own communities: to the care of families, friends and neighbours, and to the care of formal palliative support services where they exist.

There are parts of India that have developed good palliative care services such as those in Kerala, which provides the opportunity to learn from those areas that have been successful [3]. The Indian Journal of Palliative Care (IJPC) regularly reports on such initiatives. However, it is widely acknowledged that supportive and palliative care services

are rudimentary in much of rural India, and that even in the major conurbations services are patchy and dependent upon the initiative of individual clinical teams and units. The costs of establishing and medicalising such services for tens of millions of potential clients in any 1 year are massive and possibly prohibitive. In particular, the trained medical manpower is simply not available to address the full scope of the problem. Other solutions must thus be sought and found if Indian Society in general is to realise a duty of care to these patients and to minimise the consequent suffering.

In general terms, these solutions must come from a range of initiatives, which include:

1. Primary public education through schools, through community workers and the media:
 - To optimise the early presentation and diagnosis of cancers;
 - To optimise the chances of “cure”;
 - To minimise harmful practices such as smoking and tobacco chewing which are strongly associated with malignancy;
 - To create public awareness of the requirement and opportunities for development of palliative care services, and to create momentum for development of the charitable sector.
2. The recognition of the role of immediate carers, and the demands placed upon them.
3. The training and education of health care practitioners to facilitate care in the community and to exercise specific roles, as in the distribution and administration of appropriate medications and aids (for example stoma bags, catheters).
4. Support for the “alternative”, religious and traditional community of health and societal advisors, working with them rather than against them to secure incremental beneficial changes.
5. The development of physical infrastructure, including outreach clinics and appropriately staffed hospices.
6. The development of an effective charitable sector to secure and distribute funds for palliative cancer care.

The UK Experience of Developing a Palliative Care Sector

Our thoughts are influenced by the experience of the UK in developing an effective nationwide palliative care system for cancer patients. Much development has been driven by the Charitable Sector and by specialist charities, such as Marie Curie Cancer Care, a UK charity that is dedicated to the care of people with advanced cancer and other illnesses, reaching some 32,000 patients per annum; or Macmillan Cancer Care.

In the context of this paper, both these and other charities have been known to support networks of nurses in the community.

An effective national palliative care system has evolved over the past 50 years, and particularly since the late Dame Cicely Saunders undertook pioneering work in developing residential hospices such as the St Christopher’s Hospice in South London; and in educating the medical profession on the effective palliation of end of life symptoms, as in the management of severe cancer-associated pain. Nevertheless, even in an advanced health economy such as that of the UK, considerable challenges exist in providing effective palliative care services at national level.

These principles are set out clearly in the UK Department of Health “End of Life Care Strategy—promoting high quality care for all adults at the end of life”, published in July 2008 [4], which in turn built upon national level work earlier in the decade, including The NHS End of Life Care Programme; the Gold Standards Framework (GSF) Programme; the development of the Liverpool Care Pathway for the Dying Patient (LCP); and the Preferred Priorities for Care (PPC) Programme.

This strategy report [4] pointed out that:

“Around half a million people die in England each year, of whom almost two thirds are aged over 75. The large majority of deaths at the start of the 21st century follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths (58 %) occur in NHS hospitals, with around 18 % occurring at home, 17 % in care homes, 4 % in hospices and 3 % elsewhere. The demographics of death in relation to age profile, cause of death and place of death have changed radically over the course of the past century. Around 1900 most people died in their own homes. At that time acute infections were a much more common cause of death and a far higher proportion of all deaths occurred in childhood or early adult life”. This reflects the situation in parts of India today.

The report also explored the purposes in securing excellence in palliative care, noting that:

Although every individual may have a different idea about what would, for them, constitute a ‘good death’, for many this would involve:

Being treated as an individual, with dignity and respect;

- Being without pain and other symptoms;
 - Being in familiar surroundings; and
 - Being in the company of close family and/or friends.
- Moreover:

Some people do indeed die as they would have wished, but many others do not. Some people experience excellent care in hospitals, hospices, care homes and in their own homes. But the reality is that many do not. Many

people experience unnecessary pain and other symptoms. There are distressing reports of people not being treated with dignity and respect and many people do not die where they would choose to. How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services. In the past, the profile of end of life care within the NHS and social care services has been relatively low. Reflecting this, the quality of care delivered has been very variable. Implementation of this strategy will make a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socio-economic deprivation. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.

Given the clarity of the challenges set out in the 2008 UK Department of Health Report, the challenges to the Indian Health Care Community over the coming decades and as the Indian population ages cannot be underestimated. The Delivering Choice Programme currently being run by the Marie Curie Cancer Care charity highlighted the benefits of taking a whole systems approach to the delivery of end of life and palliative care.

Following a wide ranging consultation strategy, the UK Department of Health recommended a care pathway approach both for commissioning services and for delivery of integrated care for individuals which involves the following steps:

- Identification of people approaching the end of life and initiating discussions about preferences for end of life care;
- Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly;
- Coordination of care;
- Delivery of high quality services in all locations;
- Management of the last days of life;
- Care after death; and
- Support for carers, both during a person's illness and after their death.

The practical application of these principles will clearly vary considerably from one state to another, and within any one state as the structure of the health care system changes, as happens from time to time in the UK itself. The principles have led to a number of new processes, which include Advance Care Planning (ACP), formal systems to support carers and courses in higher education for professionals involved in supportive care.

Advance Care Planning

This is a formalised process of discussion between a patient with a limited life expectancy and his or her care providers [5]. The ACP process establishes clearly a patient's wishes and will usually anticipate deterioration in the patient's condition, which would impede his or her capacity to make decisions and/or to communicate wishes to others. This process may lead to Advance Decisions to Refuse Treatment (ADRT), which may specify refusal of particular medical treatments in particular circumstances [6]. Valid advance decisions, which are refusals of treatment, are legally binding. One example of an advance decision to refuse treatment is the patient-specified "Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) instruction.

The ACP process therefore enables not only the patient to voice their wishes for a time when they may no longer be able to do so. It also allows the health care team to have a clear understanding of the patient's wishes and to show appropriate leadership. Thus, painful and inappropriate interventions do not continue at the end stage of life when the patient may not have wanted this [7].

Supporting the Carers

Carers, who are primarily family members, but who may also be professional trained personnel who are allocated to the patient, may experience strain, distress and high levels of psychological morbidity during the patient's illness and beyond. Early and on-going discussions between staff and family around end of life care matters are essential. Uncertainty as to final outcome is a common problem during this phase of the patient's life, which carers find particularly hard to address. "End of life" decisions should remain with the patient wherever possible, so long as he or she is competent to make them.

Excellence in the delivery of supportive care thus requires an awareness of the contexts in which Advanced Care Planning may be appropriate, along with guidance on documentation, appropriate communication skills, an understanding of the principles of Informed Consent and the ability to judge how to give sufficient information to allow the patient to make informed decisions. This general knowledge will be supplemented by appropriate technical skills and detailed knowledge of the care needed by any particular patient, along with knowledge of the local resources that are available to deliver that care.

Formal supportive care thus integrates the science of cancer, palliative and end of life care with excellent communication skills, common sense and an understanding of human behaviour that values the individual and those of importance to them; that influences the quality of practice

and services; that enables others to strive for excellence; and that builds local, national and international clinical and research capacity in these specialties.

Higher Professional Education in Cancer, Palliative and End of Life Care

There are a range of resources for medical and other health care professionals which can help them to improve their knowledge and skills in the development of systems of palliative care and in the treatment of patients with advanced and terminal illnesses. For example, the University of Southampton (UK) runs an MSc course in Clinical leadership in Cancer, Palliative and End of Life Care. This has been developed for Practitioners of any discipline who are working for any service delivering cancer, palliative (cancer and non-cancer services) or end of life care. It might form a model for similar such courses in other health systems [8]. This course comprises of three core modules designed to empower and to create a consistent focus on the needs of the patients being served and to transform services to achieve high levels of excellence. These modules are:

- Specialist practice in cancer, palliative and end of life care
- Policy and service design in cancer, palliative and end of life care
- International and contemporary perspectives of clinical leadership in cancer, palliative and end of life care.

Research methodology is also included. The students are integrated within the internationally respected Cancer, Palliative and End of Life research group, joining this group for research seminars and research coaching, and the student's

communication skills are developed in the preparation and presentation of a formal Dissertation on a relevant topic. The course has had an international studentship, including its first student from India in 2012.

In conclusion, the provision of a universal and effective palliative care system for cancer patients is a major challenge for governments and health care providers, and a matter of considerable concern for cancer surgeons and their patients [9]. We hope that this article will help to stimulate debate and provide pointers to a way forward in India based upon the UK experience.

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