Supportive care: an overview

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Overview

- Definitions
- Models
- Implications for palliative care
- Challenges
First, what is “Palliative Care”?

NICE, 2004:
‘Palliative care is the active holistic care of patients with advanced, progressive illness.
Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount.
The goal of palliative care is achievement of the best quality of life for patients and their families.
Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.’
Why is it called ‘palliative care’?

- ‘Palliative care’ was first used as a euphemism for ‘hospice care’ in French-speaking Canada (Montreal), because ‘hospice’ meant ‘an old peoples home’
- There is still confusion in the English-speaking world about what ‘palliative care’ means
- Many still use it as a euphemism for end of life care
A new international framework for palliative care

S.H. Ahmedzai a,*,1, A. Costa b, C. Blengini c, A. Bosch d, J. Sanz-Ortiz e, V. Ventafridda e, S.C. Verhagen f, on behalf of the international working group convened by the European School of Oncology 1

• Palliative care is the person-centred attention to physical symptoms and to psychological, social and existential distress and cultural needs in patients with limited prognosis, in order to optimise the quality of life of patients and their families or friends.
‘Hospices are not only for the dying’ – but public and many professionals don’t always see that
Why has palliative care focused on end of life?

- Reflects 150 years history of palliative care development
- Dying is handled poorly in Western societies
- Pain and other types of suffering can increase at the end of life
- Humane need for society to care for its dying people
Total pain –
• Physical pain
• Emotional pain
• Social pain
• Spiritual pain
• Financial pain...
Importance of family

- Effects on quality of life
- Effects on carers and children
- Economic factors.....

Courtesy: Robert Pope Foundation
Humanity of symptom control

• BUT - For many (most?) chronic diseases, symptom palliation is the best that medicine can offer, sometimes with prolongation of life
• We need to give symptom palliation as much time and care as we give to diagnosing and treating disease
• Is it not humane to care for pain and suffering in all people, not only those who are dying?
What about ‘early palliative care’ (EPC)?

ASCO guideline based on past 7 years of studies of EPC
- Most in USA
- Most in cancer
- Most in ‘advanced’ stage of cancer

**Recommendations:** “Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment.”

“Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may offer family and friend caregivers of patients with early or advanced cancer to palliative care services.”
### Evolution of oncology

<table>
<thead>
<tr>
<th>Original aims</th>
<th>Modern aims</th>
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<tbody>
<tr>
<td>Diagnosis</td>
<td>Prevention</td>
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<tr>
<td>Cure</td>
<td>Early and accurate diagnosis</td>
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<tr>
<td>Palliation</td>
<td>Cure</td>
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<td>Prolonging life</td>
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<td></td>
<td>Palliation</td>
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<td>Rehabilitation</td>
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<td>End of life care</td>
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Increasing cancer incidence + decreasing mortality = more survivors
First UK mention of ‘Supportive care’ - 2000

July 2000

Dear Colleague

Development of Guidance on Supportive Care: Draft Proposals

Improving the provision of supportive care to meet the needs of all those affected by cancer is one of the major priority areas with the National Cancer Programme. We are using the term ‘Supportive Care’ to encompass information/communication; symptom control; rehabilitation; psychological care; social care; spiritual care; complementary therapies and support given to carers. The term applies to all stages of the cancer journey. Palliative care is therefore a major component of supportive care. The term also embraces care given by generalists and specialists.
‘Supportive care’ in cancer

MASCC definition:
“The prevention and management of the adverse effects of cancer and its treatment. This includes physical and psychosocial symptoms and side effects across the entire continuum of the cancer experience including the enhancement of rehabilitation and survivorship.”

Multinational Association for Supportive Care in Cancer
NICE (2004) defined “Supportive care”

‘helps the patient and their family to cope with cancer and treatment of it –
from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement.
It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.
..given equal priority alongside diagnosis and treatment.’
NICE (2004) Supportive Care Guidance

Topic Areas

1. Co-ordination of care
2. User involvement in planning, delivering and evaluating services
3. Face-to-face communication
4. Information
5. Psychological support services
6. Social support services
7. Spiritual support services
8. General palliative care services, incorporating care of dying patients
9. Specialist palliative care services
10. Rehabilitation services
11. Complementary therapy services
12. Services for families and carers, incorporating bereavement care
13. Research in supportive and palliative care: current evidence and recommendations for direction and design of future research

Depends on needs – NOT the stage of disease
The multiprofessional supportive care ‘virtual team’

• Palliative medicine
• Specialist nursing
• Physiotherapy
• Social work
• Chaplaincy
• Pharmacy
  • Oncology, surgical, medical specialties
  • Primary care team
  • Pain Clinic
  • Patient & public information
• Psychology
• Dietician
• Occupational therapy
• Speech therapy
• Complementary therapies
• Oncology, surgical, medical specialties
• Primary care team
• Pain Clinic
• Patient & public information
A trial looking at chemotherapy for frail or elderly patients with advanced cancer of the stomach or food pipe (GO2)

This trial is trying to find the best way to treat people with cancer of the stomach or cancer of the food pipe (oesophagus) who are not strong enough to have standard chemotherapy. The trial is supported by Cancer Research UK.

Doctors often treat advanced cancer of the stomach or food pipe with chemotherapy. A combination of drugs called epirubicin, oxaliplatin and capecitabine (EOX) is a type of chemotherapy they often use.

For some people, chemotherapy with 3 drugs is too strong, but a milder form of chemotherapy may still be helpful. For others, it may be best not to have chemotherapy at all, but to have other treatments to control cancer symptoms. This is called best supportive care. There is currently no way for doctors to be sure what will be the best treatment for each individual patient.
Systematic review of the literature for clinical trials published between 1980 and 2012 in which systemic anticancer therapy was compared with an SC-only arm and compared SC implementation with World Health Organization (WHO) published guidelines.

| Table 1. Comparison of therapies included in the definition of SC versus BSC |
|--------------------------------------------------|------------------|------------------|
| Category                                         | All N (%)        | SC N = 25        | BSC N = 48        | P-value |
| Analgesics                                       | 34 (47%)         | 13 (52%)         | 21 (44%)          | 0.50    |
| Radiation therapy                                | 32 (44%)         | 13 (52%)         | 29 (40%)          | 0.31    |
| Antibiotics                                      | 20 (27%)         | 3 (12%)          | 17 (35%)          | 0.033   |
| Steroids                                         | 19 (26%)         | 10 (40%)         | 9 (19%)           | 0.05    |
| Blood transfusions                               | 19 (26%)         | 1 (4%)           | 18 (38%)          | 0.002   |
| Psychological support                            | 13 (18%)         | 4 (16%)          | 9 (19%)           | 0.77    |
| Nutritional counseling                           | 12 (16%)         | 2 (8%)           | 10 (21%)          | 0.16    |
| Social work                                      | 9 (12%)          | 4 (16%)          | 5 (10%)           | 0.49    |
| Antiemetics                                      | 8 (11%)          | 2 (8%)           | 6 (13%)           | 0.56    |
| Antidepressants/anxiolytics                      | 4 (5%)           | 3 (12%)          | 1 (2%)            | 0.077   |
| Palliative specialist                            | 2 (3%)           | 2 (8%)           | 0                 | 0.047   |
| Spiritual support                                | 1 (1%)           | 0                | 1 (2%)            | 0.47    |
| Other therapies (e.g. thoracentesis, pleurodesis)| 12 (16%)         | 2 (8%)           | 10 (21%)          | 0.16    |
Another unhelpful concept

Cure (Curative)  Care (Palliative)

courtesy: Robert Pope
20th century view of cancer care – the WHO resource allocation model

Curative

Palliative

End of life care

Diagnosis

Death
SC aims to:

- Control the symptoms that occur as a result of the condition or its treatment and prevent complications thus allowing the individual to tolerate and benefit from active therapy more easily
- Meet a patient’s spiritual, practical, physical, social, psychological, sexual and cultural needs
- Inform patient decision making and optimise patient understanding in relation to the illness and its treatment
- Enhance health professional–patient communication
- Improve general physical and mental health
- Optimise patient comfort and ease the physical burden of the condition thus in turn improving the ability to function and reducing the impact of disability
- Help the patient and their family cope with their illness and the treatment of it
- Empower the patient and their family as well as promoting self-help and user involvement thus enabling the individuals to draw upon their own strengths.
SC may include the following, as needed:

- Issues of survivorship, palliation and bereavement
- Support groups
- Professional counselling and psychotherapy
- Rehabilitation
- Practical help
- Benefits advice
- Pharmacological and non-pharmacological interventions
- Nutritional support
Survivorship
Sheffield model of supportive care
- Total patient and family experience

Adapted from: Ahmedzai, Walsh Seminars in Oncol 2000
Sheffield model of supportive care

Fully integrated care

- Diagnostic & Screening
- Life-prolonging
- DISEASE-DIRECTED THERAPIES
- Life-maintaining
- Death
- Curative

SUPPORTIVE CARE

...information, psychology, rehab, late effects, palliative medicine, hospice, primary care, pain clinic, social care, spiritual care...

Adapted from: Ahmedzai, Walsh Seminars in Oncol 2000
Definition of supportive care: does the semantic matter?

David Hui

KEY POINTS

• Although wide variations exist among the definitions for supportive care, all of them include elements of symptom management and improvement of quality of life for cancer patients on treatments and those with advanced diseases.

• Primary supportive care is delivered by oncologists and primary care teams, providing basic symptom management and information in the front-line setting.

• Secondary supportive care is provided by teams with specialized expertise, such as palliative care, wound care, and psychiatry, on a consultation basis.

• Randomized controlled trials involving a ‘supportive care’ arm should clearly define the level of intervention and ideally involve secondary supportive care services to ensure a high standard of care delivery.
Definition of supportive care: does the semantic matter?

David Hui

Curr Opin Oncol 2014
Definition of supportive care: does the semantic matter?

David Hui

Curr Opin Oncol 2014
Sheffield model of supportive care

Who does what and when?

Adapted from: Ahmedzai, Walsh Seminars in Oncol 2000
And now – ‘ESC’

ENHANCED SUPPORTIVE CARE

Integrating supportive care in oncology
(Phase I: Treatment with palliative intent)
Who needs supportive care?

- Patients and families seeking information about the illness and treatments
- Patients and carers with psychosocial distress
- Patients with unrelieved symptoms or controlled symptoms with unacceptable toxicity
- Patients and carers who are struggling with changing aims of anti-cancer treatment
- Patients and families approaching the end of life
## Symptoms and side-effects

<table>
<thead>
<tr>
<th>Symptoms of cancer</th>
<th>Side-effects of cancer treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue and weakness</td>
<td>Fatigue and weakness</td>
</tr>
<tr>
<td>Pain</td>
<td>Pain</td>
</tr>
<tr>
<td>Appetite, nausea and bowel problems</td>
<td>Appetite, nausea and bowel problems</td>
</tr>
<tr>
<td>Breathing problems</td>
<td>Breathing problems</td>
</tr>
<tr>
<td>Sexuality and intimacy issues</td>
<td>Sexuality and intimacy issues</td>
</tr>
<tr>
<td>Problems with body image</td>
<td>Problems with body image</td>
</tr>
</tbody>
</table>
Survivorship

Sheffield model of supportive care
- Fatigue experiences

Fatigue from chemotherapy cardiotoxicity

Fatigue from anaemia due to GI blood loss

Fatigue from radiotherapy; chemotherapy myelosuppression

Fatigue from hypercalcaemia

Fatigue from cachexia

Adapted from: Ahmedzai, Walsh Seminars in Oncol 2000
## Table 1. Main adverse reactions - % all severity grades and ( ) grades at least 3 and 4

<table>
<thead>
<tr>
<th>Targeted therapy</th>
<th>Systemic manifestations</th>
<th>Renovascular</th>
<th>Skin and mucosa</th>
<th>Gastrointestinal symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Fatigue/asthenia</td>
<td>Arthralgia/myalgia</td>
<td>Headache</td>
<td>Hypertension</td>
</tr>
<tr>
<td>Cetuximab</td>
<td>9 [0]</td>
<td>[7]</td>
<td>[7]</td>
<td></td>
</tr>
</tbody>
</table>
Pains in cancer arise from the disease – and the treatment.
ALL - mucositis with intensive chemotherapy – Days 5 - 40
Why is mucositis painful?

- Destruction of protective role of epithelium
- Exposure and sensitisation of nerve endings to $H^+$, local and circulating noxious agents
- Induction of painful sensory signals and transmission to brain (via cranial or peripheral nerves and spinal cord)

ROLE OF THE IMMUNE SYSTEM IN CHRONIC PAIN *Neuroscience* 2005

Fabien Marchand*, Mauro Perretti* and Stephen B. McMahon*
Multiple myeloma – HSCT – Day 10
Chronic graft-versus-host disease in patient ‘cured’ of myeloma
Chemotherapy-induced neuropathic pain

“I get sharp electric shocks that shoot up my legs”

“When I walk it feels as I have sharp stones in my shoes”

“My feet feel like they’re burning / blocks of ice”
Chronic symptoms in multiple myeloma survivors

Living With Advanced But Stable Multiple Myeloma: A Study of the Symptom Burden and Cumulative Effects of Disease and Intensive (Hematopoietic Stem Cell Transplant Based) Treatment on Health-Related Quality of Life

Elaine Boland, MD, MRCP, Christine Eiser, PhD, Yousef Ezaydi, MRCP, Diana M. Greenfield, PhD, Sam H. Ahmedzai, FRCP, and John A. Snowden, MD

Academic Unit of Supportive Care (E.B., S.H.A.) and; Academic Unit of Psychology (C.E.), University of Sheffield; Department of Haematology (Y.E., J.A.S.), Sheffield Teaching Hospital NHS Foundation Trust; Weston Park Hospital (D.M.G.), Sheffield Teaching Hospital NHS Foundation Trust; and Late Effects Group Sheffield (D.M.G., J.A.S.), Sheffield, United Kingdom
Dimensions of survivorship in this study –
- Physical symptoms and quality of life
- Endocrine abnormalities
- Cardiac dysfunction
- Sexual problems
### Late effects in myeloma survivors

#### Pain experience

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worst pain</td>
<td>4.8 (1.3)</td>
<td>3.5 (2.0)</td>
<td>0.15</td>
</tr>
<tr>
<td>Least pain</td>
<td>1.6 (1.8)</td>
<td>1.6 (1.3)</td>
<td>0.98</td>
</tr>
<tr>
<td>Average pain</td>
<td>3.9 (2.4)</td>
<td>3.0 (2.0)</td>
<td>0.28</td>
</tr>
<tr>
<td>Pain right now</td>
<td>3.0 (2.8)</td>
<td>2.5 (1.8)</td>
<td>0.53</td>
</tr>
<tr>
<td>Pain Interference</td>
<td>3.0 (2.6)</td>
<td>3.0 (2.3)</td>
<td>0.97</td>
</tr>
</tbody>
</table>

Table 3: BPI-SF Mean (SD) for males and females (Pain range 0 -10)

- 67% of patients had sensory neuropathy
- 50% had evidence of neuropathic pain

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*Living With Advanced But Stable Multiple Myeloma: A Study of the Symptom Burden and Cumulative Effects of Disease and Intensive (Hematopoietic Stem Cell Transplant Based) Treatment on Health-Related Quality of Life*

Ellaine Roland, MD, MPH; Christine Dincu, PhD; Venu Madabushi, MD; Elisa M. Greenfield, MD; Ann H. Heron; FACP; and Julie A. Neidich, MD

Assistant Professor of Supportive Care (E.R., A.H.), and Assistant Professor of Pathology (E.A.N.), University of Michigan Department of Hematology/Inferno and Myeloma Research Laboratory, Myeloma Institute for Research and Therapy, Wayne State University, Detroit, Michigan, USA; Myeloma Research Foundation Trust, Wayne State University, Detroit, Michigan, USA; and Myeloma Institute for Research and Therapy, University of Michigan, Ann Arbor, Michigan, USA.
Late effects in myeloma survivors

Pain experience

Chronic inflammatory mediators – especially IL-6 – are important factors in pain, depression and appetite suppression.
Genetic predisposition to chronic pain in myeloma survivors

Initially increased pain after salvage stem cell transplant compared to conservative management –

• But by 2 years, transplant patients had lower pain

Pain was associated with several genetic variations –

• OPRD1 (delta opioid receptor)
• ABCB1 (drug transporter)
• SNP rs13361160 in the chaperonin CCT5 gene (generalised pain)
Principles of pain management in long-term cancer survivors

• Cancer survivors are trying to return to normal daily life
  – Prefer not to keep coming back to hospital
  – Prefer not to be drugged up
  – Want to carry on driving
  – Want to return to work and hobbies
Sheffield implementation of supportive care in haematology

- Supportive and palliative care team visits Haematology in-patient wards and day wards almost every day – often >1/day
- Consultant/trainee doctors available every day – including overnight and at weekends
- Since 2015 – clinical nurse specialist working Saturday and Sunday 09.00 – 17.00
- Joint guidelines from supportive care and haematology departments
Guidelines for supportive care in multiple myeloma 2011

John A. Snowden,¹ Sam H. Ahmedzai,² John Ashcroft,³ Shirley D'Sa,⁴ Timothy Littlewood,⁵ Eric Low,⁶ Helen Lucraft,⁷ Rhona Maclean,¹ Sylvia Feyler,⁸ Guy Pratt⁹ and Jennifer M. Bird¹⁰ On behalf of the Haematology Task Force of the British Committee for Standards in Haematology and UK Myeloma Forum

¹Department of Haematology, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, ²Academic Unit of Supportive Care, The University of Sheffield, Sheffield, ³Department of Haematology, Leeds Teaching Hospitals NHS Trust, Leeds, ⁴Department of Haematology, University College Hospital, London, ⁵Department of Haematology, John Radcliffe Hospital, Oxford, ⁶Myeloma UK, Edinburgh, ⁷Department of Clinical Oncology, Freeman Hospital, Newcastle, ⁸Department of Haematology, Calderdale and Huddersfield NHS Trust, Huddersfield, ⁹Department of Haematology, Heartlands Hospital, Birmingham, and ¹⁰Avon Haematology Unit, Bristol Haematology and Oncology Centre, Bristol, UK
What about outside cancer?

Supportive care model also works well for
• Sickle cell disease
• Haemophilia

• Rheumatology and auto-immune diseases (in future – role for stem cell transplant?)

• And of course – lung, cardiac, renal, neurology…
The big question

Not all patients with cancer or chronic disease need intensive supportive or palliative care

So - how do we know what patients’ and families’ needs are?

Answer – Holistic needs assessment!
In conclusion….

- Palliative care and supportive care NOT the same
- Supportive care is NOT ‘early palliative care’
- Supportive care is based on needs, not stage of disease – offered at all stages, including ‘survivors’
- Supportive care works best alongside disease-modifying therapies – mainly acute sector
- Some palliative care specialists can contribute to supportive care, especially in oncology – but needs a new dedicated workforce
- Future challenge – ‘supportive care for all’?
Accompanying the patient
- on the whole journey – to recovery or death