“IMPLICATIONS OF PALLIATIVE CARE IN GENERAL MEDICINE”

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Abundant Life Palliative Care
Victoria Hospital Wynberg
WHO (World Health Organization) defines palliative care as "an approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". (WHO)
Ethical considerations

• Patients diagnosed with life-threatening or terminal illness are vulnerable in their emotional state and dependence on their health care professionals (and non-professionals) for compassionate empathetic care, sensitive sharing of information to promote participation in decision-making and effective symptom management. It is essential that HCPs caring for patients with life-threatening illness base their care on sound ethical principles and practice.
Beneficence and Non-maleficence

- Benefit to the patient
- In clinical care, balance benefit of treatment vs risk of treatment
- If there is no longer any benefit to the patient withholding or withdrawing treatment is a sound medical decision which may be reached in discussion with patient, family & carers
- Continuity of care
- Non-abandonment, there is always an appropriate treatment plan
- Referral to hospice or palliative care service if symptom control is not achieved within time frame specified in individual care plan.
- Rigorous and effective professional education of HCPs to develop competence in palliative care will promote beneficence, as will effective medical & palliative care research
Autonomy

- Informed consent
- Participation in decision-making
- Confidentiality and privacy
- Refusal of treatment
- Based on good communication, assessment of patient’s understanding
- Empowerment combines autonomy & beneficence
Justice

• Distributive justice - distribution of scarce resources
• Rights based justice - equal access to health care
  • - right to palliative care
  • - right to pain and symptom control
  • - right to competent, trained clinician
• Legal justice - in accordance with the laws of the state
1. Setting

- Victoria Hospital, Wynberg, Cape Town,
- District level public hospital
- 160 beds: 2x medical wards, 2 x surgical wards, 1 paediatric ward,
- 1 overnight EU ward
• **Drainage area: Southern Suburbs**
• Uninsured population: 600 000

• **Platform service:**
  - > Local CHCs (eg Lady Michaelis in Wynberg), Level 1 hospital: FBH refer to us.
  - > Level 3 Groote Schuur Hospital

• **Emergency Unit:** 3500 patients/month  -> almost half require hospital admission

• **Outpatient clinics:** >4000 patients/month

• Medical admissions: 20/day => turnover rapid (ALS 3 days)
• Bed occupancy rate > 100%
Victoria Hospital 2011

- 2011 47 in-patient and 11 home deaths p/m
- Department of Medicine Mortality rate for last 5 years 12-15% 500 -600 of admissions p/m
- Paediatrics <5 deaths per annum
- Surgery 2-5 deaths per month
## Admissions/Deaths for 2007

<table>
<thead>
<tr>
<th>Month</th>
<th>Admissions</th>
<th>Deaths</th>
<th>%</th>
<th>HIV %</th>
<th>DM %</th>
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</thead>
<tbody>
<tr>
<td>Jan</td>
<td>323</td>
<td>31</td>
<td>9.6</td>
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<td>Feb</td>
<td>309</td>
<td>32</td>
<td>10.4</td>
<td>18.8</td>
<td>21.9</td>
</tr>
<tr>
<td>Mar</td>
<td>326</td>
<td>44</td>
<td>13.5</td>
<td>13.6</td>
<td>25.0</td>
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<tr>
<td>Apr</td>
<td>308</td>
<td>31</td>
<td>10.1</td>
<td>22.6</td>
<td>9.7</td>
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<tr>
<td>May</td>
<td>359</td>
<td>34</td>
<td>9.5</td>
<td>14.7</td>
<td>17.6</td>
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<tr>
<td>Jun</td>
<td>395</td>
<td>35</td>
<td>8.9</td>
<td>11.4</td>
<td>20.0</td>
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<tr>
<td>Mean/mo</td>
<td>337</td>
<td>35</td>
<td>10</td>
<td>16</td>
<td>19</td>
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</table>
Causes of death

- Infections, 23.9%
- Tb, 10.7%
- CVA, 14.8%
- IHD, 12%
- COPD, 8.2%
- Cancer, 6.3%
- CRF, 3.1%
- Cardiac, 2.6%
- Liver failure, 1.2%
- Lung, 0.6%
- Other, 16.6%
Mortality trends

- Trend is increase in hospital admissions
- Mortality rates remain stable 10-15%
- Change in cause of death at Victoria showing increase in number of Renal failure, Cardiac Failure, COPD as a cause of death and as a primary underlying disease
VHW distribution by age
2007
Impact of the deaths

• On medical students, interns, community service, registrars and consultants
• Nursing and other staff
• How much Training?
• Who does the training?
• Whose responsibility is the training?
Impact of the Deaths

• Patients in the ward
• Patients fear of the hospital
• Families of patients
• On communities
• Society at large
• Death is the only certainty in life
Are our doctors equipped?

- Training of doctors is changing
- Focus has changed according to disease prevalence
- E.G. HIV and TB vs NCD
- Mortality rates increase but what has happened to training
- Impact of Stress on Doctors
Place of Death?

- A Century of Change USA Data

<table>
<thead>
<tr>
<th>Year</th>
<th>1900</th>
<th>2000</th>
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<tbody>
<tr>
<td>Life expectancy</td>
<td>47 years</td>
<td>75 years</td>
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</table>

Usual place of death

- home
- hospital

Medical expenses paid

- by family
- Medicare

Disability before death usually not much
- average 2 yrs
What has changed?

• High Income countries have now emphasized Palliative Care
• Low income countries especially in Africa are lagging behind
• Why? Number of reasons
• Quadruple Burden of Disease and in Cape Town add the TIK effect
WCDH 2020 Plan

- Client Centered approach
- PHC model of preventive, curative, rehabilitation, palliation
- Improving the patient experience of the health care system
- Bringing care to the patient
Balancing Act of the Physician

• Providing the best Evidence Based Medicine
• In a resource constraint environment
• With competing patients and competing departments
• Patients have better access to information and their expectations are changing
The typical disease trajectories identified in patients with different diseases.
Aims of palliative care

• To affirm life but regard dying as a normal process.
• To provide relief from pain and other distressing symptoms.
• To neither hasten nor postpone death.
• To integrate psychological and spiritual aspects into mainstream patient care.
• To provide support to enable patients to live as actively as possible until death.
• To offer support to the family during the patient's illness and in their bereavement.
• Palliative care model incorporated into everyday Care
• Every patient deserves to die with dignity, is that between 2 patients in EM unit
• Is it alone in a bed in the middle of the night
• What would you like?
• How many of us use our service or would like to?
2. Initial spark : 2008

• Lecture by Keri Thomas : Gold Standards framework in UK
• Recurring deaths during night shifts
• Patient: MR F 28 years old, End Stage Renal failure, rejected for dialysis program = death sentence => *a move from ‘cure’ to ‘care’*
3. Problem

- Victoria Hospital M & M statistics of 2007 – 48.8% of patients died from predicted unavoidable.
- Every year 683 beds get taken up by admissions of regular revolving door patients.
- Most common repeated admissions
  - Chronic organ failure patient
  - Elderly frail patient
Problems encountered at Victoria Hospital

1. Same patient with multiple admissions
2. Poor/No symptom control
3. No long-term management plan especially once discharged from GSH not accepted for Domiciliary Oxygen, Dialysis, Cardiac Surgery
4. Ad hoc plans get made on each admission
5. Family or the patient’s carer is given minimal support
6. Hospices not able to accept patient
7. Patient dies in hospital and family feel there has been no care
4. Intervention

Public Hospital Palliative Care Program

Improve Quality of Care

Save costs
• Improved pain & symptom control
• Decrease anxiety & psychological strain.
• Improve communication between patient & health care provider
• Allow to plan for future & increase time spent with loved ones
• Support for family & carer – acceptance & bereavement
Method

- Pilot project
- Out patient program
- Multi-disciplinary team approach
- Patient support at all levels – physical, social, spiritual
- Paradigm shift form ‘cure’ to ‘care’
- Thinking ahead & making a future plan
- Recognise death as natural closure to life
**Which patient’s qualify?**

1. **Would you not be surprised if the patient dies within the next 6 months – 1 year?**

2. **Condition** | **Referral criteria**
---|---
CCF | • symptoms despite maximal medical therapy  
• ≥ 5 admissions in last 6 months  
• other associated organ involvement eg renal
COPD | • disabling SOB at rest (NYHA class IV)  
• ≥ 5 admissions in last 6 months  
• associated cardiac failure
Renal failure | • not suitable / declined for dialysis  
• End stage renal disease (GFR < 15ml/min)
Stroke | • severe disabling  
• Severe dysphagia  
• Recurrent fever & sepsis
Miscellaneous | • patient in need of surgery but not medically fit  
• severely bedridden + bedsores
Program breakdown

**In-patient stage**
- Patient identification
- Future management plan

**Out-patient program**
- 4 session program
- Linking patient & existing community resources
Support from the community

- Hospice Palliative Care Association
  - Continuous support
  - Team Training

- St Luke’s Hospice
  - Spiritual care counsellor
  - Home Base care co-ordinator

- Living Hope Hospice
  - Co-ordinating nursing sister
  - Social worker

- Rotary Club Claremont
  - Initial start-up funding for Pilot Project

Public Private Partnership
Benefits of a partnership

1. **Training:** *Introduction to PC for Multidisciplinary team*

2. **Access to resources:** St Luke’s & Living Hope Hospice
   - human resources & expertise

3. **Ongoing support with program development**

**MADE A PUBLIC HOSPITAL’s DREAM A REALITY**
6. Measurable aims

1. Improved understanding & acceptance
2. Decreased anxiety surrounding death
3. Subjective improved care delivery
4. Improved understanding of health care facilities & appropriate service seeking
5. Increase Medical Staff awareness
6. Decreased hospital admissions
7. Cost savings
7. Results of Pilot Program

Patients participation:

- 36 patients were referred to the program since mid-April 2009
- 7 of the referred patients died before the start of the program
- **11 patients were enrolled.**
- 2 of the patients enrolled died during the course of the program.
A. Disease understanding: qualitative assessment

**Patient’s Reflections**

- “for 7 years I have been asking the doctor what is wrong with my husband and no one has ever stopped and explained things to me”

- “Doctor am I going to be cured? I thought that is why I am coming to hospital”

- “when we visit there is never a doctor to talk to and if you ask the Nurse for information they say its confidential”.
B. Evaluation psychological aspects and anxiety surrounding death

Major future worries expressed by patients

- “I will not be able to support my family.”
- “Leaving behind my young child.”
- “What to expect from the disease and how it is going to end.”
- “Experiencing pain.”
- “my family will not understand what is wrong with me.”
B. Evaluation psychological aspects and anxiety surrounding death: POST-Program

SPIRITUAL CARE

- ‘for the first time I was given an opportunity to talk about the issues that were worrying me.

- ‘it was good to speak to people going through the same thing.’

- ‘I was very worried at the start of the program but now I feel like a load has been lifted...I feel free.’

- ‘it was nice to have a more than just my physical needs addressed’
C. Subjective Improvement in Quality of Care

1. Quality of Program
   - Patient’s rated each session. (1 = unhappy with session, 5 = excellent session, no changes)
   - Average satisfaction rating = 4 (very happy, minor changes)

2. Improved Quality of Life
   - Increased awareness to treat patient’s symptoms, not just disease.
   - Less time spent in hospital

3. Freedom to choose preferred place of death
   - Patients given free choice: 90% prefer to die at home, amongst family
   - Increase home deaths - All Abundant Life patients who died had home deaths

4. Quality medical attention
   - Senior doctor & medical interns spend dedicated time with patient & family

“None of the other hospitals has ever cared about me in this way...”
D. Further admissions

- 2 x admissions during the course of the program.
- 3 x admissions at 3 months after program

COST SAVING $$$
After the pilot program

- More funding USAID R6000 per month
- Appointed Elizabeth Pitout Co-ordinator
- Integrated palliative Medicine
- Actively recruiting patients
- Volunteer from USA to gather Statistics
- Expanded the use of symptom management
Research Areas

• Retrospective study comparing before and after implementation of program
• a sample size of 56 Abundant Life patients
• control group of 48 patients
• similar diagnoses, socioeconomic backgrounds, ages, and severity of illness
• Average time in the program 2.5 months
Figure 1. Number of Hospital Visits Patients Compared to Non-Aburi

Abundant Life: 1.39
Control: 1.97
Results Jan 2012

- total cost savings of R2 131 pp (PDE R1039)
- Home Deaths increased from 20.8% to 58.9%
- Reduction in number of readmissions by 29.6%
- Reduction in Length of stay
- Improved quality of care
- Improved Family support
- Abundant Life has cared for >400 patients
Since presenting data

• Groote Schuur Hospital opened Abundant Life
• R500 000 funding for 1 year and recently been extended
• I was invited to attend a 2 week visit at SCI
• Our research is pending publication
• We have improved quality of care
• The Face of Victoria has changed
**Future Vision: Integrated approach**

<table>
<thead>
<tr>
<th>Hospice (St Luke’s/Living Hope)</th>
<th>Victoria Hospital PC team</th>
<th>Day Hospital PC team</th>
<th>Community Based Services (home care)</th>
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<tbody>
<tr>
<td>End stage admission</td>
<td>Advanced medical care</td>
<td>Support Groups</td>
<td>Assistant care &amp; support</td>
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<tr>
<td>Expert Palliative Care advice &amp;</td>
<td>Specialist decision to</td>
<td>Disease education</td>
<td>Health promotion</td>
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<td>symptom control</td>
<td>cessation of further</td>
<td>Recognition of</td>
<td>Treatment adherence</td>
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Future

• Would like to see other hospitals implementing some of these very basic cost effective caring models

• Palliative care integration into general medical practice not as a referral but as an additional team member Palliative Care Sister helping the team provide better holistic care

• Improved referrals

• Funding for this type of practical and patient centered approach
Future

• We will not have enough money in public or private to provide everyone with Transplants.
• Abundant Life assisting in Education around organ Failure
• Teaming up with Organ Donor Foundations
• Hopefully also have an Educational sector around Prevention
• Promoting Healthy Living
2013

- Employed a Social Worker full post
- Employed a Palliative Care Counselor
- Opened our new offices
- Rotary Claremont supplied 65 Wheelchairs, commodes, etc
- >800 referral since 2009
- Trained 36 interns, 48 medical registrars at Victoria Hospital for 4 and 3 months
Conclusion

• Palliative Care is a right and not a privilege
• The physician should not Abandon the patient
• “sorry but there is nothing we can do”
• Questions