When, where & why (or not)? Rehabilitation in palliative care

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Lecture overview

• Palliative rehabilitation – a changing space

• Current evidence & research in progress

• Future implications – clinical practice & research
Palliative rehabilitation – a changing space

**Dame Cicely Saunders**
St Christopher’s Hospice 1967

**Balfour Mount (Emeritus Prof)**
Royal Victoria Hospital 1973

**Specialist IP PCUs, community teams**
1990s+

Function at minimum level of dependency
*JH Dietz, 1969*

No place for therapeutic nihilism
*Dr Andrew Cole 2010*

Acute hospitals, ambulatory care settings, primary care
2000s+
Finite capacity of specialist palliative care services

• WHO (2015): ↑elderly population - but its not just elderly who are dying...
• ↑prognosis – ↑ levels of disability
• Finite numbers of hospice & hospital beds
• Finite numbers of community teams
• ➡ increasing demands on primary care
Patient and family voices

Initial perceptions: patients & families in onc/haem OP unit, onc/haem/surg OP UNIT & IP palliative care

- 50% ~AKPS 80 -100, 27% AKPS 60 -70, 23% AKPS 50 – 10

- **Diminished care**: non-medically focused care, only pain relief, comfort focused
- **Diminished possibility**: place to wait for death, end to perceived hope, time of dependency
- **Diminished choice**: institutionalised dying, nothing more we can do,
  choice b/w ‘controlled dying’ (VAE) or ‘dying out of control’ (palliative care)

- Community discourse around what constitutes palliative care still has a long way to go

(Collins et al., 2017)
# Reasons why people with palliative care needs choose to end their lives

## Death with Dignity – Oregon

**Top 5 reasons to end life (N=1179)**
- loss of autonomy (90.8%)  
- unable to participate (89.4%)  
- loss of dignity (68%)  
- loss of bodily control (46.3%)  
- burden to family (42.7%)  
- pain (26%)

(Hedberg & New, 2017)

## Death with Dignity – Washington State

**Top 5 reasons to end life (N=212)**
- loss of autonomy (90%)  
- unable to participate (87%)  
- loss of dignity (73%)  
- loss of bodily control (46%)  
- burden to family (56%)  
- pain (38%)

(Washington Death with Dignity 2017 Annual Report)
Why consider rehabilitation for people with palliative care needs?

‘The soft bigotry of low expectations limits what we can achieve’

Graeme Innes, ex-Disability Rights Commissioner, Australian Human Rights Commissioner

“Effective palliation is not simply an end point but rather a means to an end – a means to ongoing participation.”

Morgan, p. 237, 2012

The voices of people with palliative care needs

- People have an innate desire
  - to be as active as symptoms permit
  - for purposeful activity (this may change over time)
  - to do enjoyable and essential activities
  - an increase in mental stimulation as function declines
- People live in the present and planning for a future, even a time limited one, gives hope
- Reciprocity, sharing responsibility with, taking care of my family is still important
- It is important to retain normal routines wherever possible
- I am reframing what equals achievement in every day life, little achievements are vitally important
- Unskilled clinicians, poor communication & fragmented care make it harder for me to adjust to decline

(Morgan et al., 2015)
Palliative care patient priorities for rehabilitation

Inpatients in a PCU, time to death – median 60 days, range 1-483 days

- Learn how to move safely, comfortably - lying, sitting, ambulating, swallowing/eating, drinking
- Exercises to maintain strength
- Provision of assistive equipment/ideas to maintain function at home & maintain self care as an IP
- Learn how to prevent pressure ulcers & falls at home
- Therapist support of patient priorities, listening to patient concerns, helping the patient learn how to adjust to changes, teach family ways to communicate with patient if communication capacity changes
- Pass on care plans to any therapist taking over care

(Schleinich et al., 2007)
Benefits of rehabilitation

- Optimise function/prevent functional decline
  - benefits for the individual
  - benefits for carers
- Includes strategies to prevent or manage
  - pressure ulcers, contractures, neuropathies, cognitive changes
- Facilitates adjustment to functional decline
- Patients supported to take informed risks
- Reduces demand on health services/changes demand - i.e. move from IP care to ambulatory & primary health care

(Franklin & Cheville., Oxford Textbook of Palliative Medicine, 2015)
Specialist palliative care physician voices

• Acknowledge that palliative care patients have rehab needs, rehab is beneficial & has an increasing role in specialist palliative care

• Ambiguity around
  - what is palliative rehab?
  - what are the achievable outcomes? Is there any real benefit?
  - does it send mixed messages?? Misleading??
  - associated with real hope or false hope

(Runacres et al., 2017)
Benefits of rehabilitation

• What is important for you in the next few weeks/months? What are your hopes?
• Introduce uncertainty: parallel planning – hope for the best, plan for the worst
• Functional Ax: established as a core part of the MDT process, routinely documented in the same way that symptoms are documented at every shift, including changes
• Use of validated outcome measures to measure changes
• Symptom control evaluated at rest and during activity
• Proactive referrals to allied health to optimise function
• Encourage patients to wear day clothes, SOOB for meals, walk to the toilet rather than commode chair, shower rather than sponge

The scope of allied health interventions to optimise function

- Allied health are usually employed in a part time capacity in Hospice/PCUs
- Scope of our role is often limited to discharge planning, the essentials, but it is broader than that
- Ask your AH to conduct an in-service regarding the scope of their role – you may be surprised...
- Increasing role in non-pharmacological symptom management – dyspnoea, fatigue, pain
- Cambridge Breathlessness Intervention Service
  https://www.cuh.nhs.uk/breathlessness-intervention-service-bis
- Growing number of papers about the scope of palliative rehabilitation
- More studies needed about efficacy of rehab interventions – need AH to engage in clinical research that is relevant to your clinical practice & your patients’ needs
Models of rehabilitation: Inpatient Hospice/specialist palliative care

- 6 hospices formed a collaborative to be ‘research active’
- Multidisc membership – medical, nursing, allied health, education
- Interest in impact of rehab on
  - patient self management (decision making, development of internal control, ↓ stress)
  - integration of exercise in everyday life
  - maintenance or ↑ level of activity
- Improved ability to cope with illness, supported setting of achievable goals
- 3 tier framework for research in palliative care
  ➤ research awareness, engagement in external projects, undertaking research

(Miller et al., 2018)
Models of rehabilitation: Inpatient Hospice/specialist palliative care

• Retrospective audit, single centre
• Specialist PCU, restorative care programme (*Dietz [1969]: preventative, restorative, supportive, palliative*)
• “Aims to regain maximum physical & social functioning possible for patients with persisting disability”
• Multidisc focus - medical, nursing & allied health Ax & interventions – (n=79)
• Successful outcomes – † AKPS or RUG-ADL scores OR discharge home (n = 16, 20%)
• Those who returned home
  - were more likely to have an AKPS of **50-70 on admission** (D/C home with mean AKPS 60.63)
  - had significantly shorter admission (mean of 17 cw mean 39 days)

(Runacres et al., 2016)
Models of rehabilitation: Inpatient Hospice/specialist palliative care

Patient perspective

• ↑ ability to complete ADLs
• ↑ mood, opportunity for self reflection
• ↑ confidence, ↑ self management

(Objective evaluation

• Statistically significant improvements in gait speed, 5xSTS time, and Short physical performance battery (SPPB)
• No change in well-being, QOL or fatigue (up or down)
• ‘Only’ 50% completed  50% is a lot!!

(Malcolm et al., 2016)
Looking ahead... Physical activity at home

RCT pilot study, feasibility, acceptability (n=24)      Function v exercise      Health economic implications?
Community dwelling palliative care clients: AKPS 60-70, independent STS, MOCA
Telehealth reported function & HRQOL, video of transfers, manual muscle testing, activPAL, bridge chair 5xSTS.
Intervention: 5xSTS

![Image of activPAL device and data chart]
Looking ahead... Screening for meaningful functional change

• How do we define meaningful clinical change? From whose perspective?
• Improved function? Maintenance of function? Discharge home? Improved carer ability to manage?
• Clinical significance versus Statistical significance

• **FIM/MBI**: not sensitive enough to detect meaningful clinical change
• **AKPS**: useful as screening tool but doesn’t detect smaller but significant functional changes

• Collaboration with UIC (MOHO) and MD Anderson Cancer Center to develop a screening tool that captures meaningful clinical change as function declines
When is rehabilitation appropriate for people with palliative care needs?

It depends... AKPS (Abernethy et al, 2005)

<table>
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<tr>
<th>40: in bed &gt;50% of the time</th>
<th>50: considerable assistance with self care</th>
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<td>60: min assist with self care</td>
<td>70: independent with self care</td>
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<td>(+/- assistive equipment)</td>
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**Restorative:** AKPS 50-70 most likely to make functional gains/maintenance/adaptation, symptom Mx

**Supportive:** maintenance of function/adaptation, symptom Mx, manual handling training with carers

**Palliative:** pressure ulcer prevention, positioning for comfort, splints, environmental modification, set up home with equipment for death at home

Goal setting & Rx implementation occurs in consultation with patient, carers & team.
Final thoughts... and questions?

• Who in your care in the last 2 weeks may have benefited from rehabilitation - but didn’t get it?
• Does your service routinely assess for functional issues as routinely as it assesses for symptom mx?
• Do you ask patients what is important for them to be doing right now?
• We need more research about the efficacy of rehab interventions for people with palliative care needs
• Consider the 3 research tiers: Where does your service fit? Where do you as an individual fit?
  1. research awareness
  2. engagement in external projects
  3. undertaking research

How do we demonstrate we make meaningful difference to patient and carer lives but also changes that have meaningful implications for the health services we work in? We can’t divorce the two...
References


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