Palliative Rehabilitation: a qualitative study of Australian practice and clinician attitudes

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Continuing the Mission of the Sisters of the Little Company of Mary
Palliative Rehabilitation

• Not a new concept
• Part of Dame Cicely Saunders’ vision for palliative care:

“The work of all the professional teams is to enable the dying person to live until he dies, at his own maximal potential performing to the limit of his physical and mental capacity with control and independence whenever possible”
Increasing recognition

Rehabilitative Palliative Care
Enabling people to live fully until they die
A challenge for the 21st century

Rehabilitative approach to palliative care a must for hospices

The Role of Rehabilitation in Palliative Care Services

ABSTRACT

How rehabilitative is your hospice?
A benchmark for best practice

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Rehabilitative Palliative Care

- Aim to maximise quality of life for patients and families
- Multidisciplinary approach
- Involve patient and family in care planning
- Optimise physical function and emotional wellbeing to highest extent possible
- Consistent with patient goals, priorities, and limitations
- Holistic

Source: Tiberini R & Richardson H, 2015
What is known?

• Australian data lacking
• No research available evaluating palliative medicine physicians’ attitudes to palliative rehabilitation
Objectives

To explore palliative medicine physicians’ attitudes towards rehabilitation, and examine Australian models of rehabilitation available within inpatient palliative care units.
Methods

• Palliative medicine physicians working in inpatient palliative care units
• Semi-structured interviews recorded, then transcribed verbatim
• Transcripts analysed using thematic analysis
• Major themes reported as results
Participants

- 20 physicians participated
- Location: VIC, NSW, SA, ACT, QLD, SA, TAS, WA
- Eleven (55%) were male
- Average of 12.5 years experience working in palliative care
- All held specialist palliative care qualifications
  - Some with dual specialisations & PhD
  - Held managerial & academic roles
Clinician attitudes – 4 main themes

1. Integrating Rehabilitation within Palliative Care
2. The Intervention
3. Possibilities
4. The message of rehabilitation
Theme 1: Integrating Rehabilitation within Palliative Care

- Different views existed
- Many believed important component of palliative care

“I think we should be offering that...it comes down to patients’ goals of care. Certainly if you can maintain peoples’ mobility it can improve symptoms, it can improve function which is part of maintaining or improving quality of life.” P12
Rehabilitation within Palliative Care

“It’s misleading and it’s misrepresenting what we do....It’s a purpose separate to whatever palliative care once was.” P11

“It probably sits within the rehabilitation field more specifically than necessarily oncology or palliative care” P16.
Existing models and practices a barrier

- Environment of inpatient units
- Clinical approach:
  - Including nursing, medical and allied health

“I think the traditional set up of how we provide palliative care probably makes it harder...the hospice model focuses often more with comfort than function. Some people would accept more function for less comfort.” P8
Inadequately resourced

- Services not resourced to effectively meet their patients’ rehabilitation needs
- Minimal ‘cross pollination’ of skills and resources

“We could perhaps think more carefully about how we utilize the resources that are there. For example here having a palliative care unit on the same campus as a rehabilitation unit, perhaps there could be a bit more cross pollination and utilization of each other’s skills.” P16
Theme 2: The Intervention

• Concepts significantly differed: time, building muscle, carer support, environmental change

“Sometimes it’s a bit different for different people. There may be one aspect that’s best treated by modifying the environment, some of them may be best treated by professional aids, some of them may possibly be ‘rehabable’, and so you sort of split the problems up and then try and identify what you can do with each of the individual things you’re working with.” P11

“They basically just need a bit more time in hospital.” P15
Consensus

- Tailored approach, goal-focused & individualised
- Multidisciplinary → Allied health input crucial

“Often I can’t judge for myself... I wouldn’t have a clue what their chances of getting up and walking or transferring or whatever it is they want are, until I’ve heard what the physio says, or the nurses or the OT.” P4
Lack of evidence base

“The literature is hard to follow in this space. There’s lots of different sorts of interventions, different intensities, different settings, different exercises and different population groups. So it’s quite hard to know what the right thing is.” P2
Theme 3: Possibilities

• Predicting patients’ capacity to restore
• Uncertainty - wanting to give people a chance
• Limitations of patient population

“You sometimes need to give people that chance...even if you think there’s no chance of them achieving it, sometimes they will prove you wrong” P14

“People continually surprise you. I sort of keep a fairly open mind about people because they never do what they’re supposed to” P11
Possibilities

“I don’t believe you can restore very many palliative care patients for all sorts of reasons...I don’t think a cancer patient has the physical capacity to build muscle” P11

“The horse has bolted I suspect ...by the time they’re extremely frail...it’s quite hard to get them back. You need to catch them earlier than that. The very frails don’t really improve that much” P2
Service possibilities

“I think one of the biggest kind of palliative care fears is the amount of time that they could potentially be admitted for, you know in terms of prognosis and rehab needs. So I think it’s something we’re trying to work on. In terms of bed turnover we’re a little bit frightened of taking them on.” P4
Theme 4: The Message of Rehabilitation

- Terminology used can influence expectations
- Useful to engage people with palliative care
- Aid transitions
- Hope
  - Positives & negatives
  - Communication
Terminology & Expectations

“One of the pitfalls in the past has been setting up unrealistic expectations. For the patient, the team and the families...that this place, if you work hard enough, if the staff work hard enough...you will get to be better than you are now...and so I think it’s set up for failure....that’s a problem with the word.” P1

“It wasn’t working in the sense for us, so we actually changed the term...it changed the expectations, so by saying it was discharge planning, people were more aware we were aiming for home.” P15
Hope

• “I think having the option of rehabilitation and...restorative care, even if we don’t always achieve it, I think it’s good also in terms of sometimes helping people to transition to a palliative, to a sort of more comfort care approach, I think can help with maintaining a bit of hope and sort of making people see that it’s not just about death and dying.” P17
Hope

“No, I really think it’s an unfair way, *it’s just holding out false hope*...I’m never quite too sure whether that’s for the patient’s benefit or the treating doctor’s benefit sometimes”. P11
Conclusion

- Varied models and attitudes exist
- Differing opinions as to optimal setting, and what palliative rehabilitation intervention entails
- Potential benefits on physical function, symptom management, hope and engagement
- Further work needed to investigate optimal approaches to deliver rehabilitative palliative care
Thank you

References
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