



Wolfson Palliative Care Research Centre &

University of Technology Sydney's

Creating Connections Palliative Care Conference

Changing Policy and Practice

Tuesday 28 June 2022

QUESTIONS AND RESOURCES

Specific questions:

Using outcome metrics and data to change policy. Dr Heather Richardson,

Question: Were these outcome measures developed for people living with cancer and now adapted for other life limiting illnesses e.g. frailty?

Answer: palliative Phase of Illness, Australian-modified Karnofsky performance status (AKPS) and the Integrated Palliative care Outcome Scale (IPOS) are all validated in palliative populations.

Question: Do you collect and store [outcomes] data electronically?

Answer: Yes.

Question: Any tips for engaging the team in this work?

Answer:

- Be curious personally and professionally about the many ways these data help complete pictures or answer wicked questions
- Think about the different audiences internally who both contribute to the data and might change practice/develop services in response
- Work out what they are interested to know
- Prepare and share the results widely to reflect these different audiences
- Encourage use of data at a variety of levels – individual patient assessment review/ MDM discussions/team conversations/Quality governance/ SMT and Board discussions
- Celebrate the stories of success that the data demonstrate
- Be vigilant on gaps in data e.g. where second and subsequent measurements are not made. Feed-back asap or ideally in real time

Comment: The Children's Palliative Care Outcome Scale (CPOS) now being developed for children and young people

Comment: For those who are not aware, there are some great resources to help the team learning on the Resolve website. The RESOLVE resources mentioned are here <https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/resolve/access-resolve-training-resources>

The St Christopher's outcomes form is attached, along with an explanatory leaflet for patients. Note that the form consists of the Integrated Palliative care Outcome Scale (IPOS) measure, along with two additional questions at the start (which are 'What is important to you right now?' and 'What would you like to achieve in the next short while?'). The two questions and IPOS have been individualised for St Christopher's Hospice with logo, etc. Please also note that the IPOS questions should not be changed, reordered or otherwise amended because these questions, asked with these words and in this order, are the ones which have been carefully tested in the palliative population. You can download the IPOS from www.pos-pal.org, including a Word version for amalgamating into your own organisational 'look'.

Palliative care aged care policy in Australia – what do researchers need to know to influence change? Ms Camilla Rowland

Question: Why is there such a disconnect - most people receiving aged care will have some palliative care needs currently or quite soon - why is this not recognised, expected, trained for?

Answer: There has been some recognition in Australia that people in aged care facilities and at home will need palliative care by the trials and pilots of integrated palliative care and aged care models in various parts of Australia, with some jointly funded by States and Australian Government. The issue here is three fold – firstly, that no Government has chosen to embed palliative care into aged care models as ongoing and recurrent services up to this point due to lack of political imperative and public demand, and secondly, there is a level of lack of understanding (and at times reluctance) by non-palliative care professionals about the right time to refer a person to palliative care services. Thirdly the infrastructure and care frameworks in many aged care provider companies have not included palliative care training and palliative care service delivery costings in their models to date as there is no regulatory requirement to do so.

Question: How is it best to influence policy-makers?

Answer: From experience in advocacy, there are three main pillars of action which provide the greatest impact. Firstly collective impact through collaboration with other significant and respected health sector bodies which is likely gain traction as palliative care on its own as a sub-acute, lower profile sector to politicians may not be as motivating for their engagement. In this situation, Palliative Care Australia has really focused on collaborations with organisations such as Dementia Australia (very high profile) to assist in highlighting the advocacy messages. Secondly, advocacy messages must be backed by evidence/research by respected institutions to provide rationale for the messages. This, with stories and case studies brings home the human aspect of health gaps to politicians and the public. Thirdly, socio economic arguments are critical, particularly where there

are significant competing priorities for health funding where the Government is trying to manage a significant deficit budget. For example, we have independent information verifying that it is cheaper to deliver palliative care in home based settings (where most people would prefer to be) than in hospitals and we can provide an estimate on return on investment.

Notes are: Collaboration, evidence, and work with respected bodies. Quality AND cost both important to emphasise. Also useful to leverage via other sectors with pressing needs e.g. primary care, public health

Question: is aged care an ethical issue – a question about the value we place on older people in society?

Answer: The issues of how we care for our ageing population draw on both ethics and the sociological perspective of our society. We know from aged care peak bodies, that our senior citizens feel that they are not valued for their contribution to society and that many of society's functions and activities are geared around the younger generations. Ethically/morally we have a duty to care for vulnerable people in our society including unwell older people. This is written in our legislative Acts and in our professional caring ethics. It is very difficult to experience equity of access and quality of care and life in our society until we recognise that all age groups are equally deserving and valued. There are some significant changes occurring with the high growth of ageing populations in western societies, as well as recognition that our ageing populations are a significant voting group which politicians and decision makers must listen to. The tide is beginning to turn on our society's view of our older generations!

This is both an ethical and sociological issue - the value we attach to older people as a society may be limited, also if not considered and value recognised this is a very short sighted approach.

Comment: It's also an existential crisis!

“Prescribing” the hand-held fan and mobility aids in practice; a systematic review. Dr Flavia Swan.

Question: can you tell us a bit more about what Inspiratory Muscle Training is/does? (this was explained).

Comment (in relation to the stigma of breathlessness): I was embarrassed today to be breathless after 5 flights of stairs. I waited until I was less breathless before I went into my meeting!

Question: Is there any correlation with fan use and time of year (cold weather and fan use might be a problem)?

Answer: The fan is often associated in people's minds with cooling and hot weather.

Implementing the Hand-Held Fan. Dr Tim Lockett.

Question: Is there evidence about fans and COVID? And comment: That's an interesting point regarding the concern of hand held fans spreading COVID-19

Answer: No evidence that we are aware of, but UK and one of Australian hospital mentioned banned fans during early part of COVID pandemic because of concerns over exacerbating spread.

Comment: An unexpected learning for me: An implementation plan for the use of hand held fans should probably include contingency planning to address fan theft!

What helps or hinders clinicians to recommend the fan in everyday practice? Mr Joshua Brown and Ms Isobel Miller

Question: Have you asked patients to promote the fan for breathlessness?

Answer: Patients – by default – do promote informally, but we have not considered formally asking them to do this.

Comment: I always see the fans as a cheap and easy win and often open patients up to some of the more difficult conversations - I do work in the community and always keep a couple in my car.

Question: If we see a patient with a new diagnosis of lung cancer, breathless on presentation, should we introduce the fan straight up?

Answer: Yes, absolutely.

Evaluation of the timeliness of a multidisciplinary assessment of breathlessness in palliative care: A quality improvement project. Angela Rao.

Question: I'd be interested to hear the actual words/language others use to explain the physiology to patients (this question not answered directly).

Answer: The PCOC Symptom Assessment Scale prompts the clinician to assess for the level of distress associated with their symptoms of breathlessness. i.e. 'is it causing you distress / is it bothering you / is it worrying you'.

At a minimum, clinicians might also ask: 1) 'What activities make you breathless, for example climbing stairs, showering, walking, or lying flat; 2) What helps when you're breathless or what do you tend to do when you're breathless and does it help (strategies, medications etc.); 3) how long does your breathlessness take to settle (i.e. does it settle quickly or does it take a long time); and/or 4) How much is breathlessness stopping you from doing things you want to do? Clinicians may also be guided by the Dyspnea-12 questionnaire, which includes terms such as: 'feel short of breath', 'cannot get enough air', 'feel like breath doesn't go in all the way', 'difficult catching breath, or 'air hunger' (<https://toolkit.severeasthma.org.au/wp-content/uploads/sites/2/2018/03/Dyspnoea12Questionnaire.pdf>)

The breathing, thinking functioning model is a good guide to approaching breathlessness with a patient <https://www.nature.com/articles/s41533-017-0024-z>

Clinical notes indicate that allied health staff (particularly physiotherapists and occupational therapists), provide education about energy conservation, positioning, pursed lip breathing exercises and the correct techniques for using a hand held fan, however, education about the physiology of breathlessness is not well documented.

DAMPEN-D; does a delirium implementation strategy improve delirium care in hospices? – a feasibility study. Dr Gillian Jackson

CLECC information

<https://www.southampton.ac.uk/assets/centresresearch/documents/wphs/Creating%20learning%20Environ.pdf>

Question: I am keen to understand a little more about how best to enable front line clinical voice to participate within co-design? Any strategies used really work well?

Answer: In terms of attendance at the workshops we held them online and kept them to a strict maximum of 2 hours as any longer than that would be unrealistic to enable multiple staff to attend. We liaised closely with our established clinical leads to hold the workshops on a day that they felt most appropriate to achieve maximum attendance.

Enabling front line clinical voice at the workshops is a little more tricky and we have had issues. Based on this, we would recommend a structured workshop with an agenda clearly detailing the aims and objectives of the workshop. Using breakout rooms is essential in our opinion as we experienced a reluctance for many staff to talk to the group as a whole and this created a scenario where a limited few dominated the entire workshop. I am more than happy to discuss this further.

Question: How did you convince Ethics to agree on an opt-out solution when seeking consent from patients?

Answer: This was by no means an easy task. We obtained special ethical approval through Confidentiality Advisory Group (CAG) and I would say the most important thing is to spend time making it very clear why seeking consent is not viable and hence why you are choosing the opt-out route. In addition, we consulted with Patient Public Involvement members when designing the opt-out poster, a really essential aspect to demonstrate. Again, I am more than happy to discuss further.

Improving electronic medical record Documentation of Nursing Plan of Care to improve South Western Sydney Local Health District's After-Hours Palliative Care Service. Misbah Faiz.

Question: I have a question about the driver / strategy of 'education' for health professionals - do you have any thoughts / comments about how we best manage this with rotational workforce clinicians and just those changing positions etc. How do we maintain this messaging?

Answer: Part of the training we received from the SPHERE-Stanford QI program included developing a sustain plan to ensure the impacts of our QI project were sustained long term. Some strategies used in this program included the documentation guidelines into orientation for new staff and having copies of guidelines readily available at key site locations. This sustain plan is still a work in progress.

Question: What/how incentivised people to change? Was it more work? Did the people doing the extra work / changing their routines get the benefit?

Answer: One of the elements of this project that made it very successful is having a very multidisciplinary team as they were able to convey key messages through their networks. It wasn't much more work because we leveraged off existing opportunities (like monthly nursing education sessions) to communicate key messages. By being opportunistic we able to minimise extra work for people. We also conveyed the message at all levels (i.e. we took a 'top down' and 'bottom up' approach).

Keynote presentation: "Multidisciplinary symptom control: walking the talk" Meera Agar

Link below for the delirium leaflet developed by Shirley H. Bush, on behalf of the Élisabeth Bruyère Palliative Care Delirium Clinical Practice Guidelines Development Team

<https://www.bruyere.org/en/Delirium>

General comments and feedback:

Comment: When we look at all our speakers [presentations] as a whole, what we are looking at is an understaffed and aging workforce managing teams of understaffed and undertrained people. To manage very complex issues for an aging and increasingly vulnerable population. This issue cannot be seen as anything but seriously political.

Comment: Should prevention include pre-emptive de-prescribing especially in frail/aged in care homes as organ failure worsens towards the end of life? We do it already but good to be framed as prevention, active rather than passive care for a very vulnerable group. Just a thought...

Lots of comments saying thank you to the speakers. For example:

- Thank you for these brief and informative sessions.
- Really great idea to display the posters virtually for those online! I did struggle to read some of the text so would it be possible to email them out afterwards? [Yes we will send out the posters too].
- Amazing work.
- Thank you for the very well put together conference. My first and hopefully not the last.
- Wonderful sessions and collaboration thank you. We need to this more often...
- It has been fantastic Fliss - thank you to you and the team +++
- Thank you-so interesting and informative.
- Thank you everyone.
- Really interesting sessions - the hybrid delivery and interaction has worked very well.
- Thank you everyone and a special well done to the medical students for their excellent study and presentation.
- A fantastic conference, well done and thank you.
- Thank you for a very interesting conference today.
- Thank you - a great morning.
- Thank you so very much for great conference!
- Thank you so much - really enjoyed.
- Thank you very much really interesting morning.
- Thank you. Really helpful.
- Thank you for great conference! Where are we able to find out about future conferences please?
