

Multidisciplinary symptom control 'walking the talk'

The example of delirium

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IMPACCT – Improving Palliative, Aged and Chronic
Care through Clinical Research and Translation

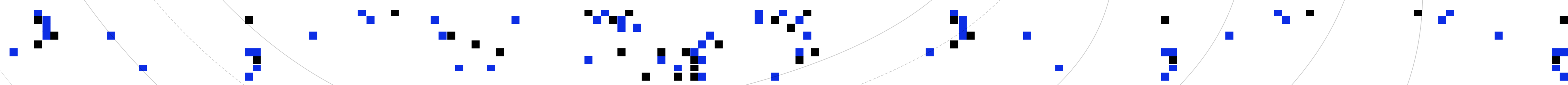


@meera_agar





Acknowledgement of Country



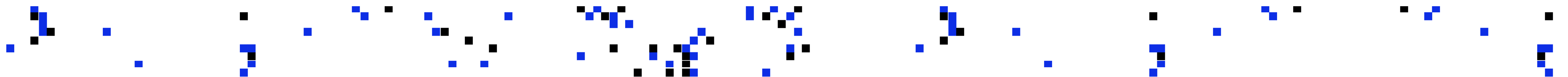
WHO

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

Palliative care is explicitly recognized under the human right to health. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals.

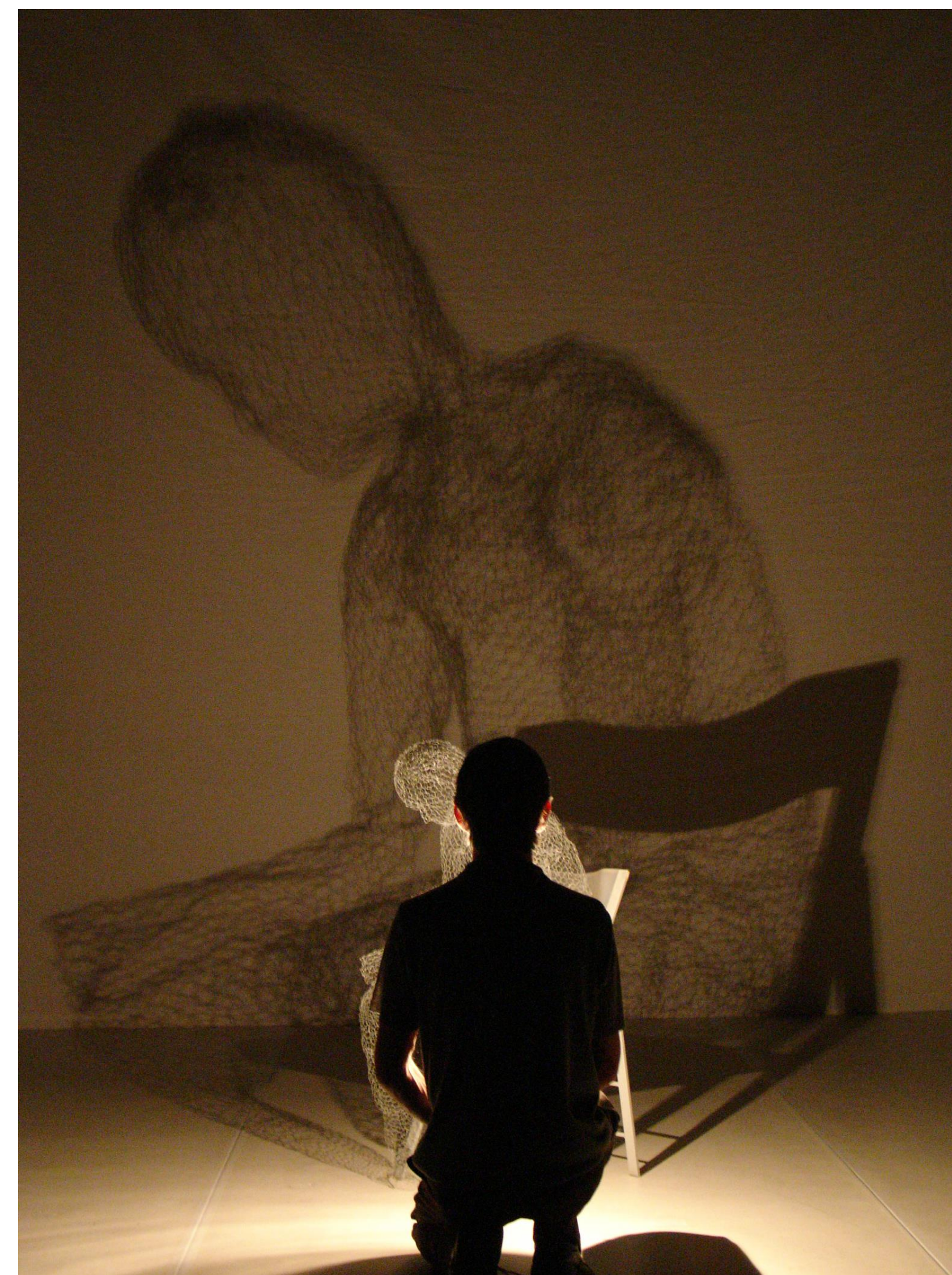
<https://www.who.int/news-room/fact-sheets/detail/palliative-care>



People.... not statistics

‘When the body falls sick, we are left not simply with a broken machine, but with a world transformed, a disease undermines our sense of self and autonomy, our relations with others, our habitual experience of space and time’

Leder 1992 in Galvin 2016



‘Takes into account preferences’ – there is a mismatch

Attributes	Patients	Bereaved Family Members	Physicians	Other Care Providers
Freedom from pain	3.07 (1)	2.99 (1)	2.36 (1)	2.83 (1)
At peace with God	3.16 (2)	3.11 (2)	4.82 (3)	3.71 (3)
Presence of family	3.93 (3)	3.30 (3)	3.06 (2)	2.90 (2)
Mentally aware	4.58 (4)	5.41 (5)	6.12 (7)	5.91 (7)
Treatment choices followed	5.51 (5)	5.27 (4)	5.15 (5)	5.14 (5)
Finances in order	5.60 (6)	6.12 (7)	6.35 (8)	7.41 (9)
Feel life was meaningful	5.88 (7)	5.63 (6)	5.02 (4)	4.58 (4)
Resolve conflicts	6.23 (8)	6.33 (8)	5.31 (6)	5.38 (6)
Die at home	7.03 (9)	6.89 (9)	6.78 (9)	7.14 (8)

*Attributes are listed in the mean rank order based on patient response. Numbers in parentheses are mean rank order, with lowest rank score (1) indicating most important attribute and highest rank score (9) indicating least important. Friedman tests were significant at $P < .001$, suggesting that rankings by each group were different than would be expected by chance alone.

Steinhauser 2000

Disparity between patient and physicians views

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %	
	Patients	Physicians
Be mentally aware	92	65
Be at peace with God	89	65
Not be a burden to family	89	58
Be able to help others	88	44
Pray	85	55
Have funeral arrangements planned	82	58
Not be a burden to society	81	44
Feel one's life is complete	80	68

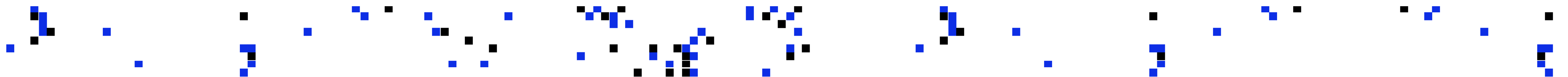
* $P < .001$ for all comparisons.

Steinhauser 2000

Distress and suffering is high – delirium in people with cancer

- More than 50% of patients with delirium resolution recall the experience
- This seems to be despite patients receiving antipsychotic treatments
 - Haloperidol 2mg every 6 hours as needed for psychomotor agitation, delusions and hallucinations up to 30mg/day (Bruera 2009)
 - 77% received olanzapine, 16.8% olanzapine/haloperidol combination, 7% olanzapine and another neuroleptic (Breitbart 2002)
- Level of distress is high
- Predictors for distress:
 - Delusions: patient distress (OR=7.9, p=0.05)
 - Performance status: caregiver distress (OR=9.1, p=0.003)
 - Perceptual disturbance: caregiver/spouse distress (OR=5.2, p=0.04)

Breitbart 2002, Bruera 2009



meaning of delirium from family perspective

Family-Perceived Meaning of Delirium and Interpretations About the Causes of Delirium

	Agree, or Strongly Agree	95% CI
	% (n)	
<i>Meaning of delirium</i>		
Sign of approaching death	59 (143)	53,65
Trying to express what the patient wanted to do or say	52 (125)	45,58
Suffering	45 (108)	38,51
A natural part of the dying process	31 (74)	25,37
Dream	25 (61)	20,31
Entering after-death world	22 (54)	17,28
Relief from actual suffering	22 (53)	17,28
Happy and welcome experience	7.0 (17)	4.0,11
<i>Interpretation About the Causes of Delirium</i>		
Pain or physical discomfort	60 (144)	53,66
Medication effects	41 (99)	35,47
Psychosis or "becoming crazy"	19 (46)	15,24
Mental weakness or death anxiety	15 (37)	11,20

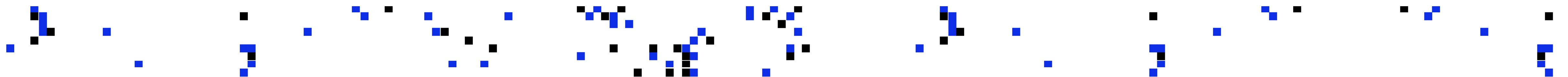
Morita 2007

Relief from real suffering

The patient said he had been out having fun or met such and such people. Maybe, he forgot his pain and suffering while he was talking. He was relaxed, being able to talk like that.

(Bereaved 4)

Namba 2007

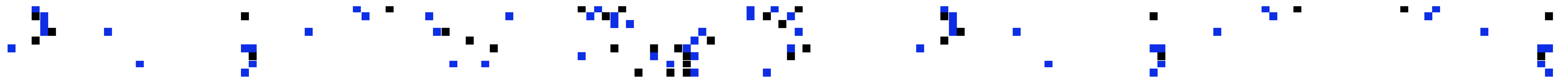


Need for information

Without understanding the cause of hallucination, we wondered if the patient had lost her soul, and we simply stopped talking, not being able to talk any longer.

(Bereaved 8)

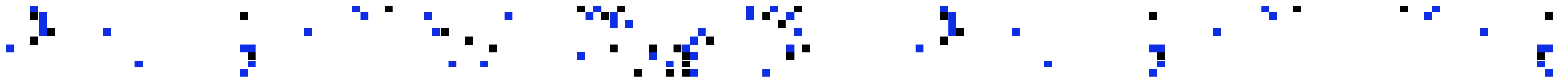
Namba 2007



Lack of partnership in or ambivalence about decisions

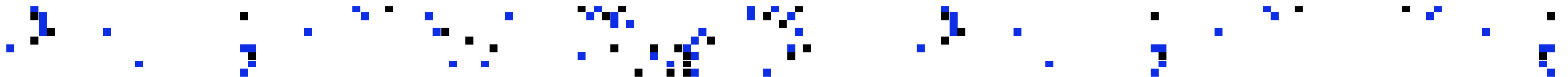
'Experienced dilemmas in relation to health care professionals who instigated treatments that they perceived added to delirium or caused other cognitive impairment such as sedation. These experiences may have results in loss of faith in the health care professionals, and further contributed to their regret and guilt about treatment decisions'

Greaves 2008, Wright 2013



Interpretation of delirium and influence on care	<p><i>“I don’t even ever use the term delirium actually. . .I would say that people were anxious or irritated or. . .I don’t know.” (Nurse, p.528)</i></p> <p><i>“It’s urgent to do something for that poor patient. . .a patient in delirium. . .inside is really in big distress.” (Doctor, p.4)</i></p>
Clinicians’ response to suffering of patients with delirium	<p><i>“The nurse always had patience and a smile. . .That human way of relating, that the patient isn’t a chart but a person, even if he is at the end of his life.” (Family member, p.77)</i></p> <p><i>“The change in her was massive and it was really quite hard to relate to her.” (Nurse, p.531)</i></p>
Roles of family	<p><i>“It meant we didn’t have any sort of deep conversations.. . . there was no saying goodbye or what are we going to do or you know anything like that.” (Family member, p.6)</i></p>

Featherstone, I et al. [Palliat Med](#). 2021 Jun; 35(6): 988–1004.



This raises the question

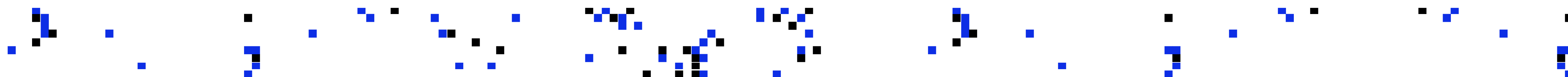
what are the person-centred outcomes we are aiming to achieve for the person with delirium at the end of life?



Humanising dimensions of care

Dimension	Definition
Insiderness	Connecting with 'inward self' – world is experienced through mood, feeling and emotions
Agency	Active participant in care
Uniqueness	Seen as an individual not a category or diagnosis
Togetherness	Need for belonging and interpersonal connections
Sense-making	Communication and information-giving
Personal journey	Retain sense of own history and continuity
Sense of place	Enhance physical environment to make people feel 'at home'
Embodiment	Expand sense of personal identity

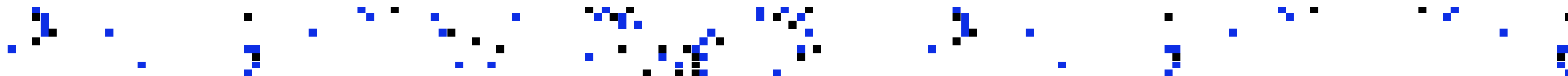
Galvin 2016. http://www.btfn.org.uk/library/directory_listings/336/Humanising%20Services.pdf



Care versus management

Don't consider	Don't consider the person with delirium as a list of fragment problems and risks
Enable and foster	Enable and foster choice
Understand	Understand their background and context, and discover what is important to them
Foster	Foster connectivity with staff, family and loved ones
Provide	Provide clear explanations about what is happening and the context
Understand	Understand that delirium disrupts sense of continuity and is unfamiliar – acknowledge and value concerns
Make	Make the environment more familiar, and consider if home is the better location for care
Treat	Treat the person with respect and dignity

Hemmingway 2012. Nursing Times 108 (40) 26-27



Precision allows us to work as a 'team'



terminal disorientated
less aware
restlessness drowsy
confused
deteriorating
terminal agitation
climbing out of bed

- nonspecific terms
- associate delirium with dying
- downplay its significance and severity
- 'separates' delirium care for those at end of life from the evidence base

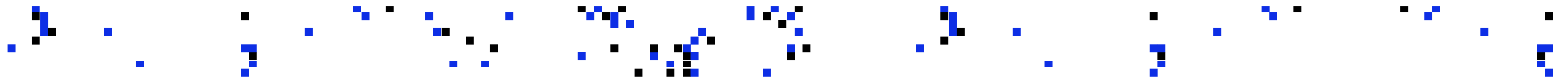
Hosie 2017. Int J of Nursing Studies. 75:123

Join the dots

gain essential
information about
the person

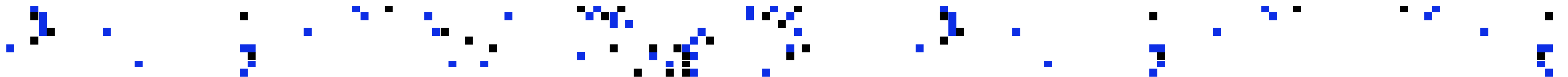
Listen to those with
greatest contact with
patient (who often
have weakest voice)

Understand the
persons goals and
wishes



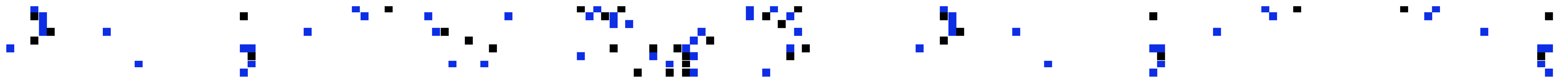
Communication

- **Coordinated and congruent communication** with person and their family about
 - What delirium is
 - cause of delirium
 - likely outcome
 - management plan



Safe space for interdisciplinary clinicians to

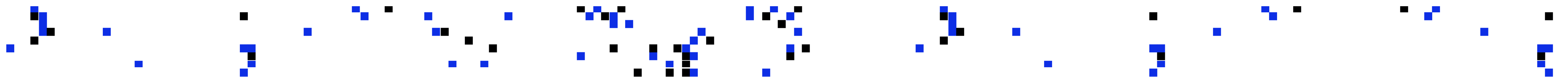
- To raise conflicts about goals of particular therapies or perceived impact on patient
- Raise the possibility of a diagnosis of delirium
- To broach impact/stress of caring for a delirious patient



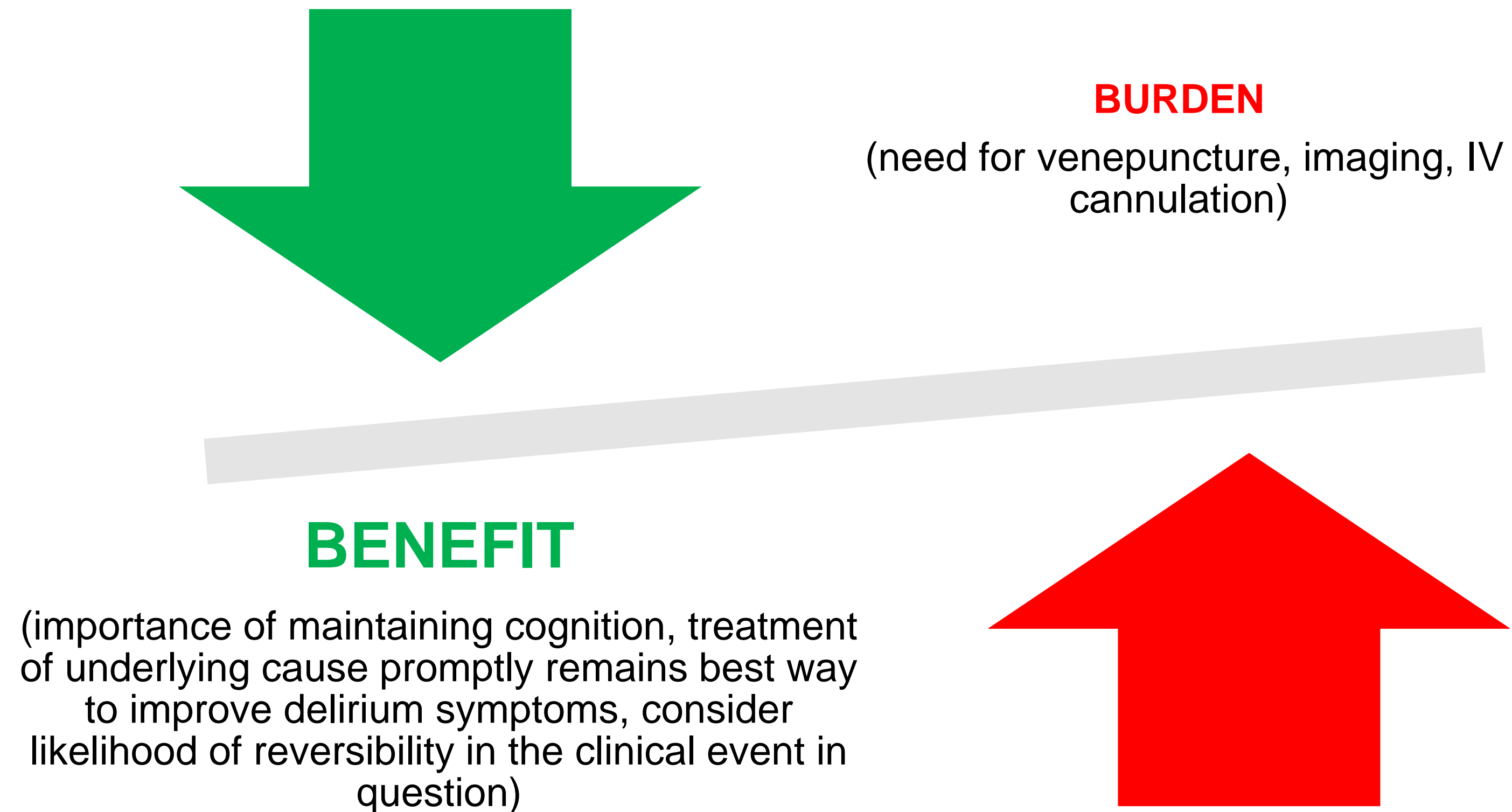
Screening and detection

- Clinicians caring for people at end of life also are have a poor understanding what delirium is
- Systems are not in place to detect delirium early
- This is aligned with the WHO definition of palliative care which highlights: ‘prevention and relief of suffering by means of **early detection and impeccable assessment** and treatment of pain and other problems...’

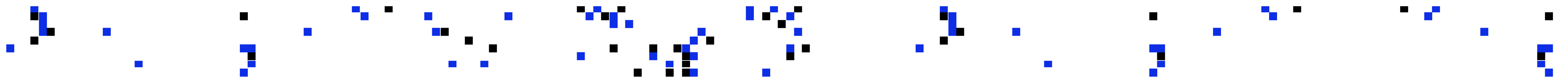
Agar 2008, Agar 2011, Hosie 2014



Active treatment of delirium precipitants or not? Whose lens do we use?



Age Ageing, Volume 49, Issue 3, May 2020, Pages 337–340, <https://doi.org/10.1093/ageing/afz171>





Understanding what the person wants

Though delirium can affect decision capacity there may be periods where it is possible to discuss options of care directly with the person themselves

Bush et al 2018

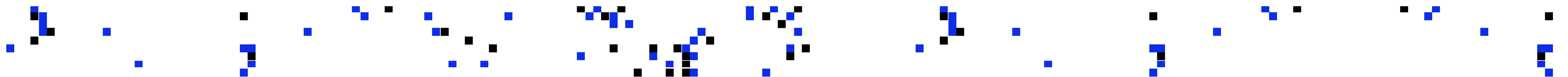
Does the evidence for non-pharmacological interventions apply?

- Many nonpharmacological prevention or treatment trials have excluded people who are 'terminally ill' but the criteria by which this was determined was not always clear

BUT likely included people who meet the definition of a life limiting illness as:

- Many studies included older patients with multimorbidity and frailty
- There were 9135 participants across 29 studies, and 23% (2090) died in hospital to up to one year later.
- We don't know adherence or the outcomes in this subgroup, but it would be reasonable to utilize these strategies for people who are able

Hosie et al. Palliat Med 2019 Sep;33(8):878-899



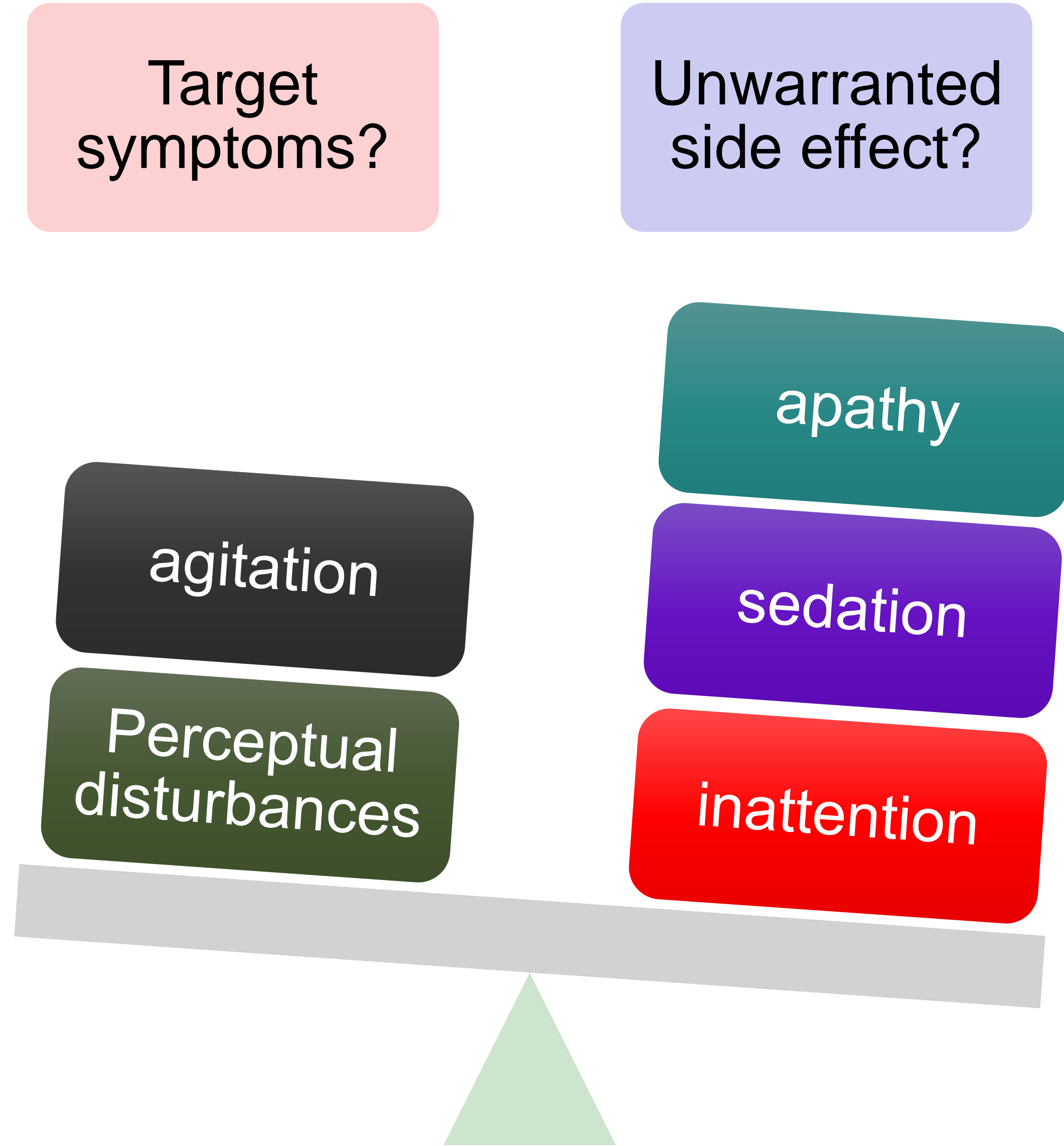
A Multicomponent Nonpharmacological Intervention
 to Prevent Delirium for Hospitalized People
 with Advanced Cancer:
 A Phase II Cluster Randomized Waitlist Controlled Trial
 (The PRESERVE Pilot Study)

Population	Four Australian palliative care units 65 enrolled patients (25 control, 20 intervention, and 20 waitlist) (approx. 1/3 of patients died within 7 days of admission)
Intervention	Delirium screening, diagnostic assessment and preventative strategies (in six domains of eating & drinking, sleep, exercise, reorientation, vision & hearing, family partnership)
Comparator	Delirium screening and diagnostic assessment
Outcomes	Highest adherence was to exercise (59%), then eating & drinking (54%), reorientation (52%) and sleep, vision, hearing and enabling family (each 41%)

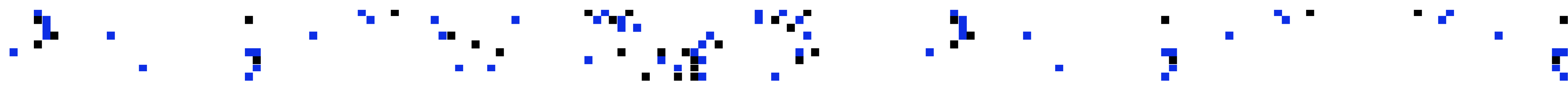
Medication or not?

Target symptoms?

Unwarranted side effect?



Do Nonpharmacological strategies ADD WEIGHT? and on which side of the scale?



Context

01

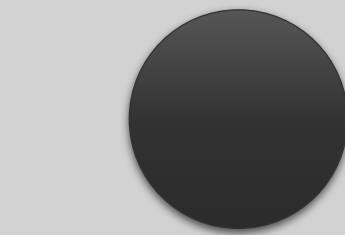
Determine
mediators of
distress

02

Concurrent
issues can
exacerbate
symptoms

03

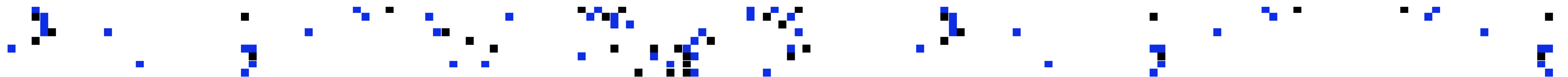
Recognize
loss of the
person the
family knew



Consider
issues of
safety

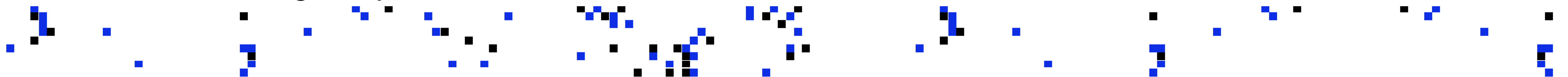
Layering in the evidence as it stands

	Agar 2017	Hui 2017
Population	Delirium in palliative care patients with target delirium symptoms associated with distress (n=247)	Hyperactive delirium in advanced cancer patients with a Richmond Agitation-Sedation Scale (RASS) score of 2 or more over the past 24 hours despite receiving scheduled haloperidol of 1mg to 8mg per day.
Intervention	Risperidone/haloperidol solution Dose titration occurred twice daily to effect by predefined increments to maximum 4mg (2mg if >65).	Haloperidol 2mg Q4h plus prn + Lorazepam 3mg on recurrence of RASS >1
Comparator	Placebo solution All participants had delirium precipitants managed and non-pharmacological measures.	Haloperidol 2mg Q4h plus prn + placebo on recurrence of RASS >1
Outcome	Behavioural, communication and perceptual problems were all worse in people treated with either haloperidol or risperidone than in those treated with placebo.	RASS at 8 hours was -2 to -3 (minimally responsive to verbal stimuli) in intervention group compared to 0 to -1 (awake alert or drowsy) in haloperidol only group



Practice points – what ‘walking the talk’ means to me in this context

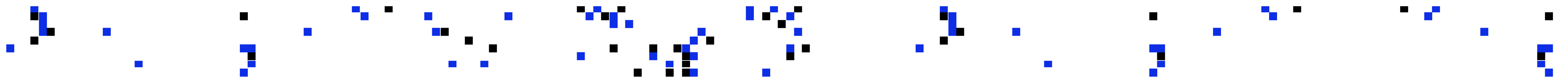
- Reflect carefully on whose distress you are aiming to treat – be cautious of treating the patient to relieve the distress of family and staff
- Articulate clearly what is the symptom(s) you are aiming to treat and the rationale for your medication choice and the intent (treating perceptual disturbance, sedation, pharmacological restraint) (extend this consideration to prn prescribing)
- Consider if all other aspects of care have been put in place
 - Is it expected these will improve situation soon and is waiting an option
- Remember prescribing is off label – this requires a responsibility of informed shared decision-making with the person or their proxy decision making
- Delirium is a medical emergency and if medication is being considered this is a senior clinician level responsibility – don't leave it to the junior staff
- Reassess regularly



Address issues of loss and grief

- Delirium and cognitive loss is an ambiguous loss
 - Behaviours are incongruent with the person they have known
 - Physically present but emotionally and cognitively absent
 - Uncertainty if the person will recover, and if recovery occurs it may be transient
- May lose opportunity for conversation/resolution
- Loss is often sudden and a significant unpredicted change
- ‘Disenfranchised’ grief
 - difficult for others to understand what has been lost, as we didn't know the person before delirium/cognitive loss occurred occurred

Boss 2014, Day 2016, Lobb 2016 (vodcast)



Is our perspective shifting?




- Australia wide online survey
- Clinicians (nurses, medical practitioners, pharmacists, nurse practitioners) who care for high proportion of people with delirium outside the ICU (geriatrics, palliative care, psychiatry)
- Most (59%) reported changing their practice since 2016:
 - Increased non-pharmacological interventions (53%)
 - Increased communication with patients and families (22%)
 - Decreased pharmacological intervention (32%)
- The reported practice change was higher in palliative care respondents than others (73% vs 53% $p=0.017$)

Original Article



Clinicians' delirium treatment practice, practice change, and influences: A national online survey

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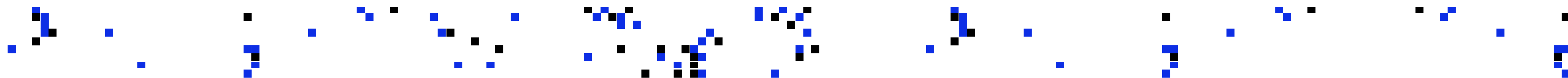


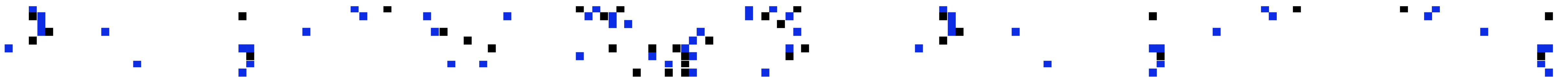
Table 3. Theoretical domains framework categorisation of all reported influences on delirium treatment practice and practice change.

Sources of behaviour	Findings per domain, <i>n</i> (%)	All	Palliative care	Other	<i>p</i> Value
Response rate, <i>n</i> / <i>d</i> (%)		348/475 (73)	118/142 (83)	230/333 (69)	0.102
Motivation	Emotion: distress (of the patient, family and other care recipients) and unsafe behaviours (for the patient, staff, family, other care recipients and visitors); influence of the patient being in the terminal phase (palliative care responders only)	187 (54)	97 (82)	90 (39)	<0.001
	Beliefs about consequences: medications considered effective for delirium; medication considered ineffective for delirium and/or harmful; not intervening thought harmful; Agar et al. trial outcomes thought not to apply to imminently dying patients (palliative care responders only)	32 (9)	12 (10)	20 (9)	0.67
	Social/professional role and identify (reflective): leadership in hospital-wide strategies	25 (7)	7 (6)	18 (8)	0.53
	Goals: Determining/acting on the patient's goals of care; safety as a goal	20 (6)	17 (14)	3 (1)	<0.001
	Social/professional role and identify (automatic): practice differed in palliative care from other specialities; customary practice; nurses' uncertainty and deference to others	20 (6)	5 (4)	15 (7)	0.40
	Beliefs about capabilities: capable nurses valued; self-confidence; perceived lack of others' competence	17 (5)	3 (3)	14 (6)	0.16
	Intention: conscious efforts to increase use of non-pharmacological interventions and/or decrease use of medication	12 (3)	8 (7)	4 (1)	0.02
	Optimism (automatic): potential for rapid resolution of delirium	1 (0.3)	0	1 (0.4)	–
	Reinforcement	0	0	0	–
	Optimism (reflective)	0	0	0	–
Capability	Knowledge: awareness of key named studies, plus other studies, academic literature, guidelines and 'updates'; training and education (including post-graduate studies in delirium, dementia, gerontology, primary health care); being involved in related research; 'common sense' and 'clinical knowledge'; as well as lack of knowledge, uncertainty and requests for further generation and dissemination of information	184 (53)	72 (51)	112 (49)	0.14
	Skills (psychological): development of interpersonal skills through clinical experience and reflection on practice; missing opportunities for skill development	25 (7)	6 (5)	19 (8)	0.30
	Memory, attention and decision processes: decision-making according to the different causes of delirium, circumstances and patients; tiredness, work burden and weariness with researchers' and advanced practice nurses' opinions	3 (1)	0	3 (1)	–
	Behavioural	0	0	0	–
Opportunity	Skills (physical)	0	0	0	–
	Physical: resource limitations; setting contribution to delirium; environmental supports; salient personal experiences	151 (43)	43 (36)	108 (47)	0.16
	Social: learning from/with colleagues; consultation with other clinicians and services; teaching/leading colleagues; feeling pressured or stymied by colleagues; interdisciplinary approach (including family); interactions with others through studies, conferences and state/national programs	72 (21)	31 (26)	41 (18)	0.10

Code: Over 50% respondents, 0–19.9% respondents, 20–49.9% respondents.

Opportunities to improve how we 'walk the talk' in delirium care

- Put front and centre that mental awareness is valued at the end of life
- Listen to the 'story' and communicate
 - Listen to the full story – meaning, context and changes over time of delirium
 - Don't make assumptions about the treatment priorities of the person and their family
 - To make informed decisions about the treatment approach the person if able and their family need to understand what delirium is, and the treatment options available to them and their relative risks and benefits (and evidence base).
 - Clarity of how we communicate as a TEAM
- Treatment
 - VALUE prevention and early detection
 - ALLOW Non-pharmacological approaches to weigh in - are more aligned with the holistic person centred approach which underpins palliative care
 - senior clinicians should be involved in decisions about pharmacological treatments



EDITORIAL

Humanizing the Treatment of Hyperactive Delirium in the Last Days of Life

Pratik P. Pandharipande, MD, MSCI; E. Wesley Ely, MD, MPH

'It is essential to focus on the humanness of medicine, to keep dying patients as comfortable and as awake as they and their families would like them to be so they can make the last few hours or days of life meaningful; and to make reasonable efforts not to cloud their sensorium unless essential to alleviate severe pain or other severe symptoms'

Pandharipande and Ely, JAMA 318 (11) 2017

