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Use of an expert panel to identify domains and indicators of delirium severity

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Abstract

Purpose Our purpose was to create a content domain framework for delirium severity to inform item development for a new instrument to measure delirium severity.

Methods We used an established, multi-stage instrument development process during which expert panelists discussed best approaches to measure delirium severity and identified related content domains. We conducted this work as part of the Better ASsessment of ILlness (BASIL) study, a prospective, observational study aimed at developing and testing measures of delirium severity. Our interdisciplinary expert panel consisted of twelve national delirium experts and four expert members of the core research group. Over a one-month period, experts participated in two rounds of review.

Results Experts recommended that the construct of delirium severity should reflect both the phenomena and the impact of delirium to create an accurate, patient-centered instrument useful to interdisciplinary clinicians and family caregivers. Final content domains were Cognitive, Level of consciousness, Inattention, Psychiatric-Behavioral, Emotional dysregulation, Psychomotor features, and Functional. Themes debated by experts included reconciling clinical geriatrics and psychiatric content, mapping symptoms to one specific domain, and accurate capture of unclear clinical presentations.

Conclusions We believe this work represents the first application of instrument development science to delirium. The identified content domains are inclusive of various, wide-ranging domains of delirium severity and are reflective of a consistent framework that relates delirium severity to potential clinical outcomes. Our content domain framework provides a foundation for development of delirium severity instruments that can help improve care and quality of life for patients with delirium.

Keywords Expert panel · Delirium · Instrument development · Severity

Abbreviations

BIDMC	Beth Israel Deaconess Medical Center
BWH	Brigham and Women's Hospital
HMS	Harvard Medical School
HSL	Hebrew SeniorLife
PI	Principal Investigator

Background

Delirium is characterized by an acute decline in attention and cognition. Affecting one in five older adults in hospitals and nursing homes [1, 2], delirium increases risk of dependence, re-hospitalization, and death [3]. This syndrome is clinically under-identified due to its varying presentation (including hyperactive and hypoactive forms), fluctuation, and because diagnosis requires a formal cognitive assessment and history of acute onset from a reliable observer [2]. Delirium is often fatal as a primary harm to patients, as a condition that increases vulnerability, and/or as a result of underlying causes or adverse hospital complications [4]. While delirium is preventable through nonpharmacologic approaches in 30–40% of cases, no definitive pharmacological prevention

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or treatment strategies have proven effective [5]. Advances in diagnosis and treatment may help to offset the $164 billion in associated costs and improve care for the over 2.6 million older adults who develop delirium annually in the USA [2].

Measurement of delirium severity is critical to advance clinical care and research in delirium. Measures are especially important because no blood or imaging test exists to identify delirium. In clinical care, delirium severity ratings are directly associated with clinical outcomes, serving as powerful prognostic tools by providing sensitive longitudinal measurements that can both detect early onset of symptoms or response to treatment [6] and inform patient and family caregiver needs after discharge [7]. Delirium severity measures can also assess burden of care on patients, family caregivers, clinicians, and the health care system. In research, delirium severity instruments are key outcome measures for clinical trials and prognostic studies, serving as continuous measures that can advance statistical approaches and maximize power [7]. Research to advance measurement of delirium severity is needed to address the variety and inconsistency in assessment, which makes comparison and integration of research findings difficult.

In a systematic literature review [7], we evaluated psychometrics of the most commonly used delirium severity instruments and identified six of high quality, the Confusion Assessment Method-Severity, the Delirium Rating Scale, and the Memorial Delirium Assessment Scale among them. This review revealed characteristics of an ideal instrument: quick administration; ease of use by minimally trained raters; yields diagnosis by criteria and a severity rating; high construct and predictive validity; and broad domain coverage across symptoms. While valuable for research purposes, our review indicated that high-quality delirium severity instruments should have immediate, relevant applications in clinical care and quality improvement efforts.

We describe our expert panel process to create a content domain framework for delirium severity, including discussing how to best measure delirium severity overall, and identifying and defining domains and indicators of delirium severity. We will use these data to inform development of a new delirium severity instrument with high clinical value that measures delirium severity at the bedside.

Methods

We conducted this work as part of the Better ASsessment of ILlness study (BASIL) [8], a prospective, observational study with the goal of developing and testing measures of delirium severity. The study was approved by the Institutional Review Boards (IRB) of Hebrew SeniorLife and Beth Israel Deaconess Medical Center in Boston, MA.

Expert panel

Expert panels are an established method used in clinical and health services research to achieve consensus on a topic [9]. We defined experts as individuals with clinical and/or research expertise in delirium. The expert panel included twelve national experts and four experts on the core BASIL team. We used a modified Delphi approach [10] wherein the core team organized and participated in the Delphi process. The core team adjudicated decisions when the national panelists could not achieve consensus. Panelists (Table 1) were interdisciplinary with an average of 23.6 years of clinical experience and 12.4 years of research experience in delirium. Per our IRB protocol, we sent potential panelists an invitation to serve as content experts; informed consent was not required.

Construct definition

An essential step of creating a new instrument is defining what is to be measured, among whom, and for what purpose [11]. We engaged our expert panel to define how to best measure delirium severity and to identify its salient dimensions, or content domains. To define how to best measure delirium severity, we asked experts to comment and vote on the relative importance of two differing approaches to measuring delirium severity: the phenomenological perspective and the impact perspective.

The phenomenological perspective conceptualizes delirium severity as the increasing frequency or intensity of delirium, or as a subjective rating of the severity of factors contributing to a delirium diagnosis, including level of consciousness, cognitive impairment, and neuropsychiatric symptoms. The impact perspective conceptualizes delirium severity in terms of the magnitude of impairment caused by delirium in fulfilling social roles (e.g., family member, patient). That is, the phenomenological perspective focuses on what delirium *is* (e.g., Is the patient disoriented?) while the impact perspective focuses on what delirium *does* (e.g., Can the patient bathe independently?).

Identification of content domains

Content domains are labels that provide a high order organizing structure, in this case, for delirium severity symptoms. Identification of content domains is an integral step of instrument development [12]. As broad constructs, content domains can be comprised of multiple subdomains and provide a framework for identifying potential instrument items and for rating items to be included in a measure. To ensure that our expert panel constructed content

Table 1 Description of expert panel ($n = 16$) for identification of content domains of delirium severity

All panelists				Mean (range)
Years of caring for patients with delirium				23.6 (5–34)
Years conducting research with patients with delirium				12.4 (1–30)
Frequency of contact with patients with delirium				*n*
Daily				3
Weekly				5
Monthly				4
A few times a year				3
No contact				1
Subgroups of panelists	Profession	*n*	Geographic location	*n*
Core research team experts ($n = 4$)	Geriatrics	2	Massachusetts	3
	Measurement	1	Rhode Island	1
	Social work	1		
National experts ($n = 12$)	Anesthesiology	1	Alabama	1
	Critical Care	1	Colorado	2
	Geriatrics	1	Connecticut	1
	Hospital medicine	1	Maryland	2
	Neurology	1	Massachusetts	2
	Neuropsychology	1	Missouri	1
	Nursing	1	New York	1
	Occupational therapy	1	Pennsylvania	1
	Physical therapy	1	Tennessee	1
	Psychiatry	1		
	Psychology	1		
	Surgery	1		

domains that included aspects of the delirium experience relevant to patients, family caregivers, and clinicians, we supplemented the expert panel process with qualitative interviews of patients ($n = 18$), family caregivers ($n = 16$), and nurses ($n = 15$) [13]. Our team identified three themes common to these groups' delirium experience: Symptom Burden (disorientation, hallucinations/delusions, impaired communication, memory problems, personality changes, sleep disturbances); Emotional Burden (anger/frustration, emotional distress, fear, guilt, helplessness); and Situational Burden (loss of control, lack of attention, lack of knowledge, lack of resources, safety concerns, unpredictability, unpreparedness). These themes captured the shared burden of delirium and provided content domains to inform our development of separate patient and family caregiver delirium burden instruments to measure each group's subjective experiences of in-hospital delirium [14]. We used these domains as context in considering content domains for delirium severity in the present study.

Expert review of content domains

Informed by the systematic review [7] and the qualitative interviews [13], the core team (SKI, ERM, RNJ, ES) proposed initial domains of delirium severity. The goal was to identify five to ten key domains covering a range of severity and reflecting a consistent framework for delirium severity that would be relevant to potential clinical outcomes. The initial four domains were: (1) Neurocognitive (subdomains: inattention; disorganized thinking; altered level of consciousness; disorientation; cognitive impairment); (2) Psychiatric-Behavioral (subdomains: emotional lability; anxiety, including fear and sense of unease; depression, including apathy and withdrawal; anger, including irritability and hostility; hallucinations, perceptual disorder or distortion; delusion; psychomotor agitation; and psychomotor retardation); (3) Functional (subdomains: sleep disorder, including insomnia, hypersomnolence, and sleep cycle reversal; and decline or low performance of self-care activities, including

poor postural control, transferring, gait/walking, poor oral intake, incontinence, disheveled appearance, and inability to use sensory aids effectively); and (4) Somatic-Medical (subdomains: vital sign instability; oxygen saturation > 93%).

Round 1

We emailed initial domains to the national expert panelists with a rating form for content domains, requesting return of the form by email prior to the first panel meeting. The review form listed each domain, its potential subdomains, and working definitions based on established sources [15–26]. We asked panelists to review each domain and to indicate if each subdomain should be included, excluded, or if they were uncertain. We also asked panelists to add missing domains or subdomains, to comment on the domains, subdomains, and their definitions, and on potential measurement challenges. All ratings and comments were processed by the core team.

We held the first expert panel teleconference in Boston in early March, 2015. Panelists joined in person or by phone and discussed the construct of delirium severity, including whether the instrument should reflect the phenomenological or impact perspective. The panel then discussed review results for the content domains, focusing on domains for which there was less than a supermajority (< 66%) vote to include or exclude. A two-thirds majority implies that more than twice as many votes cast were in favor of the position, a common parliamentary rule for decision-making [27]. This meeting familiarized panelists with the conceptual underpinnings of each domain [28] and enabled robust discussion. The panel revised the content domains at the meeting, and the core team refined them afterwards.

Round 2

We emailed the revised content domains to panelists with another rating form for ratification and/or further modification. We asked panelists to complete the form and return by email prior to a second panel meeting held in late March, 2015. At the meeting, panelists discussed domain definitions and review results, focusing on controversial domains until they reached consensus on final content domains and their definitions.

Results

Sixteen panelists participated in Round 1, and thirteen participated in Round 2. We present ratings of content domains and subdomains in Table 2 and how content domains changed in Table 3. Figure 1 depicts the final content domain framework. We present final definitions of content domains and subdomains in Table 4.

Defining measurement of delirium severity

Panelists felt that both the phenomenological and impact perspectives should be reflected in measuring delirium severity. The rationale was that the phenomenological perspective, with its focus on frequency, intensity, and pattern of symptoms, guides clinicians' (medical, nursing, physical and occupational therapy) treatment, management, and evaluation of treatment effectiveness. In a complementary role, the impact perspective, with its focus on cognition, behavior, and function, is important for formal and informal caregivers in terms of communication, safety, provision of direct care, and discharge planning. A panelist summarized,

> If we could address both approaches it would be fantastic. The phenomenological approach seems more geared toward professional staff, but I see the impact approach as having more real-world application for families and direct care staff such as nursing assistants.

Another explained,

> What delirium does is the more interesting of the approaches as it has the potential to lead to interventions, but obviously if you are misclassifying delirium, your intervention studies won't be as useful. Hence my reason for including both approaches.

Panelists felt both perspectives were needed to accurately measure delirium severity and create a patient-centered instrument. With clear consensus, this topic was not discussed in Round 2.

Initial review of content domains

Following Round 1, all content domains remained the same: Neurocognitive, Psychiatric-Behavioral; Functional; and Somatic-Medical; however, panelists disagreed on some subdomains. Twelve subdomains did not have a supermajority (Table 2). In the Neurocognitive domain, this included the subdomain, any cognitive impairment. In the Psychiatric-Behavioral domain, debated subdomains were delusion, emotional lability, anxiety/fear/sense of unease, anger/irritability/hostility, and depression/apathy/withdrawal. In the Functional domain, under the subdomain of decline or low performance of self-care activities, most of the subsubdomains were debated, including poor postural control, transferring, gait/walking, poor oral intake, incontinence, and disheveled appearance. These subdomains advanced to Round 2 for further rating and discussion.

Panelists suggested additions, exclusions, and edits to the domain framework. Panelists suggested two subdomains,

Table 2 Expert panel ratings of delirium severity content domains and subdomains across rounds of review

Domain: subdomain (and order of discussion)	Round 1 ($n=16$ experts)				Round 2 ($n=13$ experts)			
	Inc	Exc	Unc	Status	Inc	Exc	Unc	Final decision
1. Psychiatric-Behavioral: psychomotor agitation	16	0	0	Include	–	–	–	Include
2. Psychiatric-Behavioral: psychomotor retardation	16	0	0	Include	–	–	–	Include
3. Psychiatric-Behavioral: hallucination, perceptual disorder or distortion	15	0	1	Include	–	–	–	Include
4. Psychiatric-Behavioral: inappropriate behavior	11	1	4	Include	–	–	–	Include
5. Neurocognitive: disorientation	15	0	1	Include	–	–	–	Include
6. Neurocognitive: disorganized thinking	14	0	2	Include	–	–	–	Include
7. Neurocognitive: inattention	14	1	1	Include	–	–	–	Include
8. Neurocognitive: altered level of consciousness	13	1	2	Include	–	–	–	Include
9. Neurocognitive: language disturbance	11	0	5	Include	–	–	–	Include
10. Neurocognitive: memory impairment	11	0	5	Include	–	–	–	Include
11. Functional: sleep disorder, insomnia, hypersomnolence, sleep cycle reversal	11	3	2	Include	–	–	–	Include
12. Psychiatric-Behavioral: delusion	10	1	5	Discuss	10	2	1	Include
13. Psychiatric-Behavioral: emotional lability	10	2	4	Discuss	5	7	1	Include
14. Psychiatric-Behavioral: anxiety, fear, sense of unease	8	6	2	Discuss	5	6	2	Include
15. Psychiatric-Behavioral: anger, irritability, hostility	7	2	7	Discuss	7	3	3	Include
16. Psychiatric-Behavioral: depression, apathy, withdrawal	6	6	4	Discuss	5	4	4	Include
17. Neurocognitive: any cognitive impairment	7	1	8	Discuss	6	6	1	Include
18. Functional: transferring [decline or low performance of self-care activities]	10	1	5	Discuss	10	3	0	Include
19. Functional: disheveled appearance [decline or low performance of self-care activities]	9	5	2	Discuss	10	2	1	Include
20. Functional: gait, walking [decline or low performance of self-care activities]	8	4	4	Discuss	10	2	1	Include
21. Functional: poor oral intake [decline or low performance of self-care activities]	8	5	3	Discuss	10	3	0	Include
22. Functional: incontinence [decline or low performance of self-care activities]	7	4	5	Discuss	8	4	1	Include
23. Functional: poor postural control [decline or low performance of self-care activities]	7	4	5	Discuss	9	2	2	Include
24. Somatic-Medical: vital sign instability	5	8	3	Exclude	–	–	–	Exclude
25. Somatic-Medical: impaired oxygen saturation	4	9	3	Exclude	–	–	–	Exclude
26. Somatic-Medical: presence of physical disorder	2	8	6	Exclude	–	–	–	Exclude
27. Functional: inability to use sensory aids effectively	3	7	6	Exclude	–	–	–	Exclude

Inc include count, *Exc* exclude count, *Unc* uncertain count

memory impairment and language disturbance, for addition to the Neurocognitive domain. In the Functional domain, the sub-subdomain of inability to use sensory aids effectively was excluded as it would be "hard to accurately assess" due to feasibility constraints because patients who require glasses or hearing aids often do not have them in the hospital. Also in the Functional domain, panelists suggested that sleep disorder/insomnia/hypersomnolence/sleep cycle reversal be changed from being its own subdomain to be a sub-subdomain of the Functional subdomain of decline or low performance of self-care activities.

Debated themes

Panelists debated three themes during discussion of content domains: reconciling clinical geriatrics and psychiatric content; mapping symptoms to one specific domain; and accurate capture of unclear clinical presentation.

Panelists had difficulty reconciling clinical geriatrics and psychiatric content due to differently defining terms, such as hallucination, delusion, and disorganized thinking, or due to different considerations of etiology. For example, for the subdomain of delusion, panelists debated whether to call the subdomain suspiciousness, whether it "might be rolled under a cognitive impairment domain", or combined with hallucinations. One panelist asserted that in the case of delirium, delusions "are more often the reflection of disorganized thinking than true thought disorder".

For the subdomain of anxiety under the Psychiatric-Behavioral domain, comments ranged from, "…some of the emotional factors may reflect issues other than delirium that are common in hospitalized patients and result in a false

Table 3 Evolution of content domains and subdomains of delirium severity across rounds of expert panel review

	Identified by BASIL Investigators	Following review Round 1	Following review Round 2
Domain	Neurocognitive	Neurocognitive	Cognitive
Sub-domains	Inattention	Inattention	[Made into its own domain, Inattention]
	Disorganized thinking	Disorganized thinking	Disorganized thinking
	Altered level of consciousness	Altered level of consciousness	[Made into its own domain, Level of consciousness]
	Disorientation	Disorientation	Disorientation
	Cognitive impairment	Any cognitive impairment	Cognitive impairment
		Memory impairment	[Included in subdomain of cognitive impairment]
		Language disturbance	[Included in subdomain of cognitive impairment]
Domain	Psychiatric-Behavioral	Psychiatric-Behavioral	Psychiatric-Behavioral
Sub-domains	Emotional lability	Emotional lability	[Excluded]
	Anxiety/fear/sense of unease	Anxiety/fear/sense of unease	[Included in new domain, Emotional dysregulation]
	Depression/apathy/withdrawal	Depression/apathy/withdrawal	[Included in new domain, Emotional dysregulation]
	Anger/irritability/hostility	Anger/irritability/hostility	[Included in new domain, Emotional dysregulation]
	Hallucinations/perceptual disorder/distortion	Hallucinations/perceptual disorder/distortion	Hallucinations/perceptual disorder/distortion
	Delusion	Delusion	Delusion
	Psychomotor agitation	Psychomotor agitation	[Included in new domain, Psychomotor features]
	Psychomotor retardation	Psychomotor retardation	[Included in new domain, Psychomotor features]
		Inappropriate behavior	Inappropriate behavior
Domain	Functional	Functional	Functional
Sub-domains	Sleep disorder- insomnia/ Hypersomnolence/sleep cycle reversal	[Moved under decline or low performance of self-care activities]	Sleep disorder- insomnia/hypersomnolence/ sleep cycle reversal
	Decline or low performance of self-care activities:	Decline or low performance of self-care activities:	Decline or low performance of self-care activities:
	Poor postural control	Poor postural control	Poor postural control
	Transferring	Transferring	Transferring
	Gait/walking	Gait/walking	Gait/walking
	Poor oral intake	Poor oral intake	Poor oral intake
	Incontinence	Incontinence	Incontinence
	Disheveled appearance	Disheveled appearance	Self-care/appearance
	Inability to use sensory aids effectively	Inability to use sensory aids effectively	[Excluded]
		Sleep disorder	
Domain	Somatic-Medical	Somatic-Medical	[Excluded]
Sub-domains	Vital sign instability	Vital sign instability	[Excluded]
	Oxygen saturation > 93	Oxygen saturation > 93	[Excluded]
Domain			Emotional dysregulation
Sub-domains			Anxiety/fear/sense of unease
			Depression/apathy/withdrawal
			Anger/irritability/hostility
Domain			Psychomotor features
Sub-domains			Psychomotor agitation
			Psychomotor retardation

Table 3 (continued)

Domain	Inattention
Domain	Level of consciousness

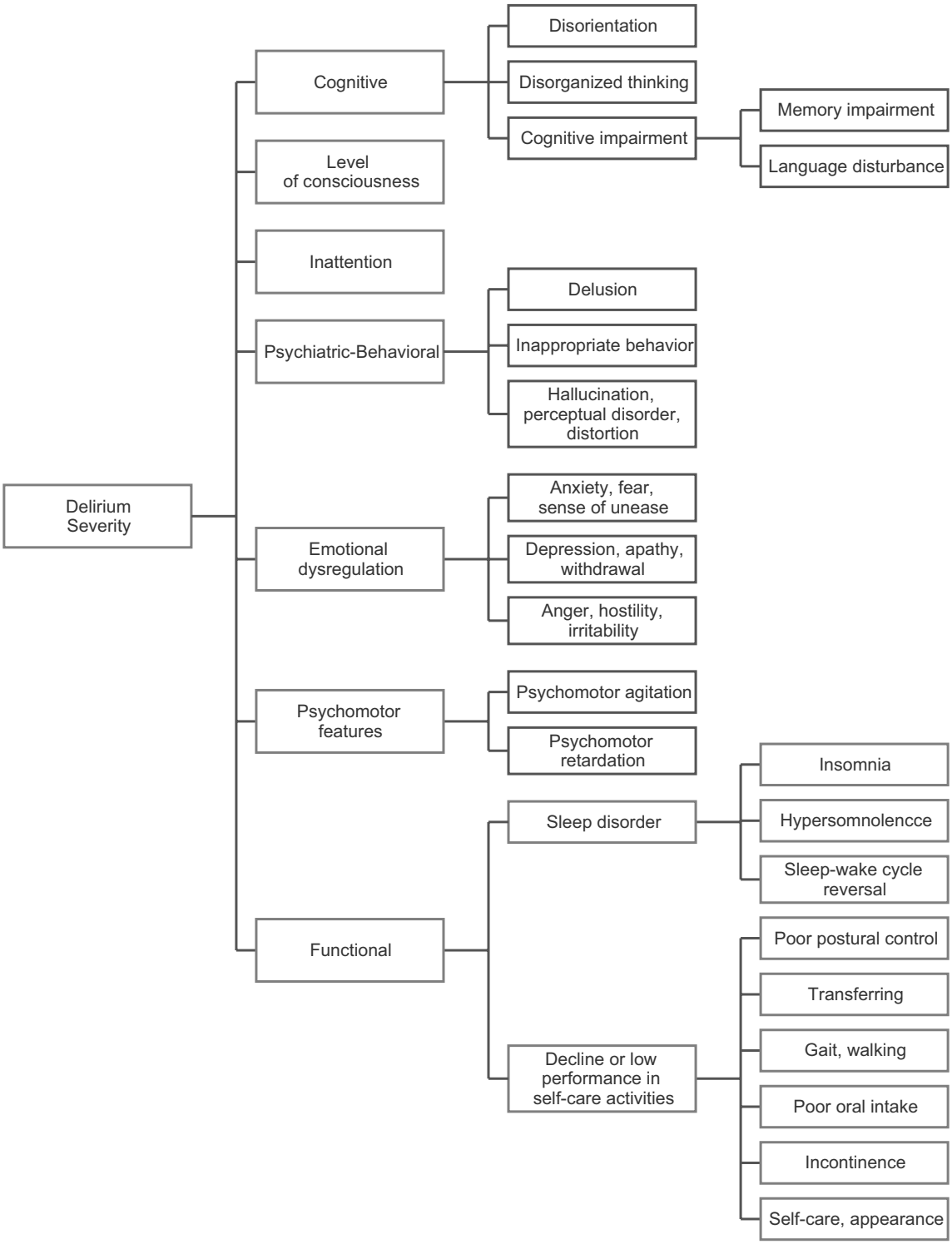

Fig. 1 Delirium severity content domains

Table 4 Final definitions of delirium severity content domains and subdomains

Domain and subdomain	Definition
Cognitive	Difficulties in cognitive abilities [15]
Disorientation	Lack of orientation to time, place, or person [16]. Typically manifested by errors on orientation items in cognitive testing, thinking they are somewhere other than the hospital, using the wrong bed, or misjudging the time of day [17]
Disorganized thinking	Thinking that is disorganized or incoherent [17] as manifested by rambling, irrelevant, or incoherent speech or conversation [16], unclear or illogical flow of ideas, unpredictable switching from subject to subject [17], or that demonstrates faulty reasoning [18]
Cognitive impairment	Evidence of impairment by formal cognitive testing, including memory, executive functioning, language, or visual-spatial abilities [16–18]
Level of consciousness	Consciousness that is other than alert, typically reduced (such as difficulty keeping awake during examination or difficult to arouse), but also vigilant or hyperalert (overly sensitive to environmental stimuli, startles very easily) [17]
Inattention	Reduced ability to direct, focus, sustain, and shift attention [19], typically manifested by the patient being easily distractible, having difficulty keeping track of what was being said [17], or needing to repeat questions because attention wanders [16]
Psychiatric-Behavioral	Symptoms characteristic of abnormal thoughts and behavior patterns
Hallucinations/perceptual disorder/distortion	Perception-like experiences that occur with (perceptual disorder, distortion) or without (hallucination) an external stimulus [20]
Delusions	Fixed beliefs that are not amenable to change in light of conflicting evidence [20]
Inappropriate behavior	Behaviors that (i) interfere with patient care and (ii) would not be considered within the norms or appropriate or safe behavior in the hospital setting. These behaviors often reflect confusion or agitation. Examples include: pulling at tubes or dressings; repeatedly attempting unsafe behaviors (such as climbing over side rails); undressing inappropriately; combative behavior; calling out; and yelling loudly or swearing [17]
Psychomotor features	Unusually increased or decreased level of motor activity [17]
Psychomotor agitation	An unusually increased level of motor activity compared with the norm, indicating restlessness or agitation, repetitive movements (such as grasping/picking at bedclothes, or tapping fingers), or making frequent sudden shifting of position [17]
Psychomotor retardation	An unusually reduced or slowed level of motor activity compared with the norm, such as sluggishness, staring into space, staying in one position for a long time, or moving very slowly. Decreased spontaneity of movement, and decreased verbal and motor responses are characteristic [17]
Emotional dysregulation	Dysregulation in the form of atypical symptom patterns related to anxiety, fear, apathy, depression, and anger
Anxiety, fear, unease	Anxiety: inner turmoil based on expectation of future threat. Fear: response to real or perceived immediate threat [19]. Sense of unease is a synonym for anxiety
Depression, apathy, withdrawal	Hallmark symptoms include anhedonia (decreased ability to experience pleasure from positive stimuli or a degradation in the recollection of pleasure previously experienced [20]) and dysphoria (general dissatisfaction)
Anger, irritability, hostility	Angry mood (e.g., irritability, reactivity), and aggression (verbal and physical). Negative social cognitions (e.g., interpersonal sensitivity, envy, disagreeableness), verbal aggression, and efforts to control anger. Anger is distinguished by attitudes of hostility and cynicism and is often associated with experiences of frustration impeding goal-directed behavior [21]
Functional	Dysfunction or decline in sleeping, performance of self-care activities, and continence
Sleep disorder	Inability to sleep, stay asleep, or excessive or inappropriate sleepiness
Insomnia	Inability to fall asleep, waking up too early and being unable to get back to sleep, or restless, interrupted sleep
Hypersomnolence	Excessive sleep, manifested by late awakening, early sleep onset, or daytime sleeping
Sleep cycle reversal	Prolonged awakening at night, excessive sleeping during the day, often associated with confusion about time of day
Decline or low performance of self-care activities	Usually manifested by an acute decline in an activity for which the patient was previously independent. For each of these activities, the decline could be either avolitional (inability to initiate the activity) or attentional (inability to effectively attend to the activity). Note that this acute decline should also not be better explained by a new focal disorder (e.g., gait difficulty due to a new hip fracture)

Table 4 (continued)

Domain and subdomain	Definition
Poor postural control	Inability to maintain a comfortable posture in bed, evidenced by a contorted posture (e.g., limbs under the body), limbs or head hanging off the bed, or falling out of bed
Transferring	New inability to get in and out of bed or a chair
Gait, walking	New difficulty initiating walking, or new instability of gait leading to an increased risk of falls
Poor oral intake	Acute decline in feeding, drinking, and swallowing mechanisms that make it difficult to maintain nutrition or hydration, and increase risk of aspiration (choking)
Incontinence	Acute inability to maintain regular toileting habits, or to request assistance with toileting, leading to urinary and/or fecal incontinence
Self-care, appearance	Poor maintenance of grooming/hygiene as evidenced by acute inability to wash, brush teeth, comb hair, or shave (men)

positive" to "this is tough because hospitalized patients have a lot to be anxious about."

Panelists also debated the Psychiatric-Behavioral subdomain of emotional lability. One suggested, "In the spirit of not including everything, this seems to be one symptom that may not pertain specifically to delirium." Another agreed that emotional lability may not be a core feature of delirium, but should be included: "[Emotional lability is] associated with delirium, but [is] not central. Other psychiatric problems may be causing this." Still another panelist wanted emotional lability to "encompass anxiety and anger".

In the same domain, for the subdomain of hallucination/perceptual disorder/distortion, a panelist commented on the etiology of hallucinations:

> I would include, because unlike anxiety, depression, and anger, in my experience, people don't hallucinate as a psychological reaction to their illness. They may hallucinate related to a drug or the disease process or sleep deprivation.

A second theme was mapping symptoms to one specific domain when symptoms were often relevant to multiple domains. For example, in the Psychiatric-Behavioral domain of inappropriate behavior, a panelist responded,

> Consider the importance of overlap with anger and agitation subdomains. I think BASIL wants an inclusive but streamlined (efficient) list of domains. It seems to be that the acting out associated with anger and irritability could be a kind of inappropriate behavior.

Regarding the subdomain of depression, a panelist commented, "this could be captured by the altered level of consciousness and the psychomotor retardation domains". Another stated, "Apathy [is] also [a] key feature of behavioral variant frontotemporal degeneration. Distinguish from psychomotor retardation." In the Neurocognitive subdomain of altered level of consciousness, a panelist noted,

> There is some controversy here… but I vote to include within the construct of delirium. When the altered level of consciousness becomes so severe that it is no longer delirium but something else is a topic for discussion.

Panelists wished to be mindful of how to best formulate items that would accurately capture symptoms that are clinically difficult to distinguish. For example, in the Neurocognitive subdomain of disorganized thinking, a panelist cautioned, "sometimes it can be difficult to distinguish inattention from disorganized thinking… so we are going to have to work on the items carefully." For the Psychiatric-Behavioral subdomain of delusion, a panelist added,

> These can also be hard to assess in the hospital. There is a fair amount of strange stuff that happens in the hospital, e.g., being awoken every two hours to ask if you need a sleeping pill. It can sometimes be hard to distinguish fact from delusion.

Relatedly, in the Functional domain's sleep disorder subsubdomain, a panelist debated,

> This is considered a core feature of delirium, and I think we'll have to include it. On the other hand, it really is hard to assess in the hospital setting since sleep disorders are nearly universal.

Discussion of controversial domains and subdomains

Following Round 2, panelists agreed to include all twelve of the debated subdomains advanced from Round 1. The Psychiatric-Behavioral domain discussion was as follows.

Delusions

Some were concerned about measurement issues because delusions are difficult to quantify and define. Panelists

discussed that delusions are also present in other psychiatric disorders such as dementia and Alzheimer's Disease. It was noted as important in measurement to consider new delusions not present at baseline. Ultimately, while panelists agreed that delusions do not necessarily indicate greater delirium severity, panelists retained the delusions subdomain as a feature important for assessing delirium severity.

Emotional lability

Panelists chose to exclude the subdomain of emotional lability. While acknowledged as present in most patients with delirium, panelists felt that emotional lability did not pertain specifically to delirium, was hard to judge at the bedside, and did not correlate with delirium severity.

Anxiety, depression, and anger

While anxiety/fear/sense of unease, depression/apathy/withdrawal, and anger/irritability/hostility may not be specific to delirium, panelists included these subdomains due to their possibly reflecting hyper- or hypoactive delirium and due to depression affecting clinical outcomes such as independence, function, and quality of life. It was additionally considered that BASIL defines severity in terms of clinical outcomes.

In the Neurocognitive domain, panelists discussed global cognitive impairment as so unrecognized in the hospital population that this subdomain would not be useful in differentiating patients with and without delirium. Experts opted to retain more specific areas of cognitive impairment, such as memory, executive functioning, language, and visual-spatial abilities.

In the Functional domain, panelists retained the sub-subdomains of the decline or low performance of self-care activities subdomain with discussion as follows.

Transferring

Panelists discussed transferring as possibly being part of self-care ability or of emotional dysregulation, but ultimately included transferring in self-care because they felt it would be difficult to operationalize the latter. Panelists agreed that it was important to include transferring as a measure of physical function and as an indirect way of assessing burden of care, patient safety, and discharge.

Disheveled appearance

Panelists debated this subdomain because in the hospital, all patients look disheveled, and nurses can offset patients' self-care inabilities. Panelists ultimately included disheveled appearance because personal hygiene and grooming are basic Activities of Daily Living.

Gait/walking

Some argued to exclude gait/walking because mobility in hospitals has declined significantly, with many hospitals placing patients on bed or chair 'arrest' where alarms ring if they rise. Others felt that gait is important for assessing the family burden of care; this perspective gained panel support and gait/walking was included.

Poor oral intake

Panelists deemed this subdomain non-specific to delirium as it is affected by pain medication, hospital diet, and bowel conditions; however, poor oral intake was included as a key functional impairment that contributes to caregiver burden and which is useful for assessing patients, especially those with hypoactive delirium.

Incontinence

Arguments for excluding this sub-subdomain were that clinical care may make patients functionally incontinent, and that incontinence is not helpful for delirium severity; however, incontinence was included because panelists felt incontinence unexplained by another clinical condition would be useful data.

Poor postural control

Panelists noted poor postural control as an issue for many patients, not just those with delirium, but felt that poor posture is useful in identifying hypoactive delirium. Hence, this sub-subdomain was included.

Finalization of content domains

Panelists suggested changes to the structure of domains and subdomains. Both inattention and level of consciousness, formerly subdomains of the Neurocognitive domain, were considered as "central" and "core criteria" for delirium meriting their own domains. The Neurocognitive domain was renamed "Cognitive" to be more general. The subdomain of memory impairment was ultimately included in the Cognitive subdomain of cognitive impairment. Discussion centered on distinguishing acute from chronic memory impairment and how to capture new memory impairment. Panelists also debated whether this is a primary feature of delirium or "an epiphenomenon of the disturbance/lack of awareness of

the environment and alertness that are presumably pathognomonic of a delirium episode." The cognitive subdomain of language disturbance was also ultimately included in the subdomain of cognitive impairment because "incoherent speech may be due to other factors" and could be "difficult to differentiate from underlying impairments".

Three subdomains of the Psychiatric-Behavioral domain, anxiety/fear/sense of unease, depression/apathy/withdrawal, and anger/irritability/hostility, were subsumed under a new domain, Emotional dysregulation. Panelists made this decision because they felt that delirium is a disorder of both cognitive and emotional life, both important. The Psychiatric-Behavioral subdomains of psychomotor agitation and psychomotor retardation were likewise moved to a new domain of Psychomotor features. The subdomain of inappropriate behavior was ultimately excluded due to potential overlap with multiple domains and subdomains, e.g., Functional, anger, agitation.

In the Functional domain, sleep disorder/insomnia/hypersomnolence/sleep cycle reversal was reinstated as its own subdomain rather than as a sub-subdomain of decline or low performance of self-care activities because it was considered a core feature of delirium. The Somatic-Medical domain and its subdomains were excluded because they are not related to delirium severity, and there are many confounders to these measurements, e.g., illness, medications.

The final seven content domains and their subdomains were: (1) Cognitive (subdomains: disorientation; disorganized thinking; cognitive impairment); (2) Level of consciousness; (3) Inattention; (4) Psychiatric-Behavioral (subdomains: delusion; inappropriate behavior; hallucinations/perceptual disorder/distortion); (5) Emotional dysregulation (subdomains: anxiety/fear/sense of unease; depression/apathy/withdrawal; anger/irritability/hostility); (6) Psychomotor features (subdomains: psychomotor agitation; psychomotor retardation); and (7) Functional (subdomains: sleep disorders- insomnia/hypersomnolence/sleep–wake cycle reversal; decline or low performance of self-care activities, including poor postural control, transferring, gait/walking, poor oral intake, incontinence, and self-care/appearance).

Discussion

We have described our expert review process as an early phase of developing a delirium severity instrument. We believe this work represents the first application of the science of instrument development to delirium. We involved interdisciplinary clinicians at each step of the process, which is of fundamental importance for this complex concept, particularly because there is no external reference standard for delirium. Incorporating clinical judgment rigorously and systematically was critical to our process [29]. Conducting interviews with patients and family caregivers informed our identification of domains related to quality of life by enabling us to consider subjective assessments of delirium burden. Integration of patient, family caregiver, and clinician perspectives allowed us to create a patient-centered, clinically relevant content domain framework for delirium severity using a clinimetric approach.

An issue that arose among panelists in establishing domains and subdomains was reconciling psychiatric and internal medicine perspectives. We ultimately opted to use terms familiar to non-psychiatric clinicians (e.g., internal or family medicine providers) versus classifying domains and subdomains using a psychiatric context. This decision reflected our vision of developing an instrument to enhance measurement of delirium severity at the bedside.

The many instruments and approaches for diagnosing delirium have created difficulties in terms of clinical recognition and scientific advancement. For example, a meta-analysis found post-operative delirium incidence ranging from 4 to 53% [30], due in part to use of different case identification tools. Existing instruments to measure delirium severity have various shortcomings [7]. Our identification of content domains of delirium severity provides a basis for development of instruments with maximum clinical sensibility and relevance. While our domains and subdomains may relate to a variety of neurological, neurodegenerative, or psychiatric diseases, the specific constellation of signs and symptoms and panelists' weightings reflect the underlying construct of delirium severity. As we develop a new delirium severity instrument, we plan to create items that capture either the phenomenological or impact perspective as important future work.

Limitations

Limitations to this work include the following: (1) Three panelists were unable to participate in Round 2; however, thirteen participated consistently, and those unable to participate provided feedback; (2) Most panelists were from the east coast. Greater geographic diversity may have added to our data; (3) Although we included nurses in our qualitative work to identify content domains, our panel did not include nursing home staff or other non-family caregivers who may have contributed important perspectives on the impact of delirium; (4) Our panel focused on delirium in older adults across clinical settings (e.g., critical care) and did not address all age groups, thereby limiting generalizability; (5) We must acknowledge that the core team organized and participated in the Delphi process and gave direct input when national panelists could not achieve consensus. Panelists were aware that the core team would only make final adjudications for contentious points. While potentially biasing, the only such occurrence was separating Inattention

from Neurocognitive as a domain; (6) While domains and subdomains were reached via consensus of an interdisciplinary expert panel, we acknowledge that various specialties might define or conceptualize these constructs differently.

Conclusions

We have identified and defined domains and subdomains of delirium severity, illustrating that delirium severity is not a unidimensional construct. Content domains will inform item development for new long- and short-form instruments to measure delirium severity, which we will validate with existing severity measures and clinical outcomes. Use of an instrument that captures all aspects of delirium severity can improve care and quality of life for patients with delirium.

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Compliance with ethical standards

Conflict of interest CHB discloses consultation and a data share with Medtronic. DC discloses receiving honoraria from the Commission on Accreditation in Physical Therapy Education. All other authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants for whom informed consent was required per IRB review.

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