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Editorial

Clinical Endpoints that Matter in Dementia Practice

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Dementia medicine has moved rapidly in the last two decades, with major advances in diagnostic imaging, fluid biomarkers and nosology. Yet most everyday decisions in the clinic and on the ward are still guided by much more prosaic questions. Will this person fall in the next three months? Can they remain safely at home? Will an acute illness precipitate delirium and permanent loss of function? How close is the caregiver to a breaking point? An editorial for a neurology journal is not the place for generic advocacy. It is the place to be precise about what we should measure, how we should analyse it and how we should report it so that data can be compared across centres and can actually inform practice.

A useful starting point is a minimum assessment set that is brief, standardised and predictive of events that matter. Most services already use a global cognitive screen such as MoCA or HMSE. That alone is not enough. Functional status should be captured with an instrument that aligns with supervision and care needs, for example CDR sum of boxes, because this is what drives bed occupancy and community resource use, An informant based tool such as IQCODE remains available in early or atypical presentations where rehearsal and routine can mask decline at the bedside. Mobility should be quantified in a reproducible manner. Gait speed over a short course or a time five times sit to stand can be collected in minutes and carries independent information about falls, institutionalisation and morality. Simple checks for hearing and vision should be treated as integral parts of the assessment, not optional extras, because uncorrected sensory loss magnifies apparent cognitive impairment and behavioural disturbance and is often modifiable. A brief frailty measure adds prognostic depth by indicating resilience or vulnerability to acute stressors and treatment. Routine bloods and neuroimaging retain an important role, but their use should be guided by the likelihood of altering diagnosis or management rather than habit.

Once a standard assessment is in place, the next question is how interventions are specified. Vascular risk management is central for many patients with dementia, yet target setting is often borrowed from middle aged populations without accounting for age, comorbidity and frailty. Protocols should make these adjustments explicit, including monitoring intervals and thresholds for de-intensification. Symptoms that erode cognition and function such as depression, anxiety, sleep disturbance and pain require structured assessment and treatment under the same clinical pathway as memory complaints. Exercise prescriptions need clear parameters. Frequency, intensity, time and type should be written down, along with progression and safety rules, so that physiotherapists and community teams can deliver a reproducible programme that builds strength, balance and endurance. Correction of sensory loss through hearing aids or cataract surgery should be regarded as core intervention. The effect of communication, social participation and caregiver's burden is often greater than that of symptomatic cognitive agents. Caregiver education should be short, pragmatic and tied to the local system. Basic communication strategies, safe handling, hydration, and nutrition routines, and a simple plan for deterioration that includes contact points reduce avoidable admissions. Drug initiation should always be documented alongside a clear treatment goal, a review date and a stop rule. Deprescribing ought to follow a structured approach that considers anticholinergic load, sedative burden, drug interactions and local formularies.

Delirium is a major determinant of trajectory in dementia, yet delirium prevention and detection are inconsistently embedded in care pathways. A low burden bundle can be implemented without

sophisticated infrastructure if it is integrated into existing documents. Adequate hydration, early mobilisation, appropriate analgesia, sensory aids at the bedside, bowel and bladder care and sleep preservation without routine sedatives should appear in admission proformas and ward round checklists. These elements are already individually familiar to clinicians but they gain power when applied as a consistent set. Short follow up contacts at around seven and thirty days after discharge, by telephone or clinic visit, provide opportunities to detect emerging confusion, medication problems or functional decline before they escalate into emergencies. Such reviews are relatively inexpensive, stabilise trajectories and generate process measures that can be audited over time.

Digital tools are increasingly promoted in dementia care. Their usefulness is determined much less by sophistication than by fit with real households. In most contexts a phone first approach with offline capability, low interaction burden and clear outputs is appropriate. Simple prompts for medication and fluids, small daily activity counts such as sit to stand repetitions, and single item checks on sleep or mood are more likely to be used and interpreted correctly than complex dashboards. Data handling needs to be conservative, with storage on device by default and explicit consent for any upload. Clinicians should assume that connectivity may fail or be unavailable, which means that every digital function requires an equivalent low tech pathway that does not delay care.

If we want results to travel between centres, we need shared definitions of outcomes and time points. A core dataset suitable for both clinical and research use is achievable. At minimum, services should collect cognition, function, mobility, behavioural and psychological symptoms, caregiver's strain, falls, emergency department visits, hospital admissions, medication changes with reasons and adverse events with dates. Using harmonised time points such as baseline, three months and six months, then annual review, permits meaningful comparison and pooling of data. When this foundation exists, registry based and cluster randomised designs can be run within routine care to answer questions about follow up intensity, exercise dose, delirium bundles or caregiver support models with high external validity.

Equity considerations are not separate from methodological quality. In resource constrained settings, including much of India, the assessment and outcome set must be compatible with primary care and community delivery. The compact battery described above can be administered by nurses, therapists or trained community health workers if escalation criteria are clear and tools are validated in local languages. Adaptations for literacy should preserve constructs rather than alter them. Educational material needs to be concrete and visually supported. Caregiver's strain, often borne by women in the household, should be measured routinely and linked to defined responses such as respite, group education or social work referral. These variables predict safety events and hospital use and therefore belong in core neurology metrics rather than in optional appendices.

Editorial policy can reinforce this technical orientation. Authors should be encouraged or required to register protocols where feasible and to nominate a single primary endpoint that corresponds to a clinical decision. Reporting should focus on baseline adjusted change with confidence intervals and minimal clinically important differences when established, rather than long lists of uncorrected p values. Handling of missing data should be described in plain terms. Subgroup analyses need a priori justification grounded in biology or service configuration, or they should be clearly identified as exploratory. Standard tables can greatly reduce ambiguity. One table should define the population and setting, list inclusion and exclusion criteria and summarise baseline characteristics that matter for generalisability. A second should specify the intervention with sufficient procedural detail to allow replication, including staff roles, dose, progression and stopping rules, adherence measures, co-interventions allowed and planned follow up. Outcomes and adverse events should be reported at agreed time points with absolute numbers and confidence intervals.

None of this is conceptually novel, but consistent implementation remains patchy. Dementia trails and service evaluations often collect rich datasets that are difficult to interpret outside the originating centre because core measures and analysis choices vary. A more disciplined approach to endpoint selection and reporting would make it easier to aggregate evidence, benchmark services and, most importantly, translate results into decisions that matter to patients and caregivers. Falls, delirium, functional decline, emergency utilisation and caregiver strain are not softer or less neurological than cognitive test scores. They are simply closer to the events that determine how people with dementia live and how services allocate finite resources. If neurology journals reward work that treats these outcomes as first class citizens, the field will move in a direction that is both scientifically coherent and clinically useful.