

Setting research priorities for NMOSD & MOGAD

Aligning patient & clinician perspectives

Summary of findings

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The Sumaira Foundation

Prioritizing research – executive summary

Significant opportunities to improve focus of & advance research efforts

- While many experts applaud the tremendous recent advances in scientific understanding, diagnosis, treatment & management of NMOSD & MOGAD, significant challenges & unmet needs remain to be addressed
- Patients & their families/caregivers have clear perspectives on important aspects of their conditions they feel need further research & progress, as do the clinicians & researchers working on these conditions
- On many topics, patient & clinician perspectives align on high-priority areas needing further research; yet on several others, perspectives differ, often in important & significant ways
- This report outlines where patient & clinician perspectives align and where they differ, proposing a prioritized research agenda for NMOSD & MOGAD as a way forward to improve diagnosis, treatment, management & outcomes

Background & context

NMOSD & MOGAD are rare neuroimmune conditions

Both can lead to serious, often life-changing, disabilities

- Neuromyelitis Optica Spectrum Disorder (NMOSD) and Myelin Oligodendrocyte Glycoprotein Antibody-Associated Disease (MOGAD) have undergone a dramatic transformation over the last 10 years from poorly understood conditions to distinct disease entities with some targeted therapies
- While clinically overlapping in presentation and symptomatology, NMOSD and MOGAD are immunopathologically distinct, with different underlying disease mechanisms at work
- NMOSD operates as an astrocytopathy where AQP4-IgG antibodies trigger complement-dependent cytotoxicity and destroy astrocytes at the blood-brain barrier, while MOGAD functions as an oligodendrocytopathy targeting myelin oligodendrocyte glycoprotein on the outermost myelin sheath layers (1,2)
- Both conditions can lead to significant and often permanent loss of vision, mobility impairments, neuropathic pain, and incontinence, with progressive worsening if relapses are not prevented

Epidemiology of NMOSD & MOGAD

Highlights based on limited published research to date

- Epidemiological data collected from seven population-based studies across Europe, Asia and the Americas between 2020-2023 established that:
 - NMOSD prevalence is approximately 1 per 100,000, with annual incidence of 0.029 to 0.90 cases per 100,000 person-years, depending on geographic region and ethnicity (16-21)
 - MOGAD prevalence ranges from 1.3-2.5 per 100,000, with annual incidence of 3.4-4.8 per million (22-24)
- In Black populations, NMOSD prevalence is up to 10 per 100,000 while in East Asian populations, the prevalence is 3.5 per 100,000. Among Caucasian populations, MOGAD appears approximately twice as prevalent as AQP4-positive NMOSD
- The demographic profiles diverge dramatically: NMOSD shows a striking 9:1 female predominance and clear racial predilection affecting Black populations at up to 10 per 100,000 (ten times higher than general population rates), while MOGAD displays minimal sex bias (1.2:1 female-to-male ratio) and no obvious racial preponderance
- Approximately 30% of MOGAD cases occur in pediatric populations, where it comprises 35-40% of acquired CNS demyelinating syndromes in children, compared to NMOSD's predominant adult onset

Current research landscape

Diagnostic and therapeutic advances

- Substantial progress has been made in four key areas: refining diagnostic criteria, understanding disease mechanisms, developing targeted therapies, and global access and equity
- The 2023 consensus diagnostic criteria for MOGAD have brought much-needed clarity to disease boundaries and diagnosis, as both MOGAD and NMOSD were historically misdiagnosed as multiple sclerosis (MS) (6–9)
- However, significant disparities persist, and the rapid advancements in scientific insights contrast sharply with some critical treatment gaps for MOGAD & seronegative NMOSD
- There have also been intensive research efforts into optimal relapse-prevention strategies (8, 10)

Current research landscape

Clinician research priorities

- Clinician priorities center on advancing the scientific and clinical understanding of these diseases, emphasizing research that addresses diagnostic accuracy, including refining antibody assay techniques and updating diagnostic criteria
- Clinicians also prioritize understanding pathophysiological mechanisms and conducting randomized controlled trials to evaluate new immunotherapies, especially for seronegative NMOSD and MOGAD where evidence gaps are most pronounced (1–3)
- Current research agendas focus heavily on optimizing treatment algorithms, understanding predictors of relapse, and improving long-term outcomes through disease-modifying therapies (5,13,14)

Current research landscape

Patient perspectives on unmet needs & research priorities

- Patient priorities, in contrast, emphasize research that directly impacts daily life & quality of care
- Patients consistently identify reducing diagnostic delays as a critical need—many experience years of misdiagnosis before receiving appropriate care
- They prioritize improving access to approved therapies and minimizing treatment-related side effects (for example, surveys show over 80% of NMOSD patients experience chronic pain and fatigue, yet these symptoms are rarely primary endpoints in trials)
- Patient surveys consistently highlight the need for research into symptom management, rehabilitation, and strategies to prevent disability accumulation
- Perhaps most importantly, patients emphasize addressing the financial and psychosocial burdens associated with chronic disease management, including the need for equitable access to care and therapies (6)
- Similarly, caregivers also cite emotional stress and financial strain as persistent unmet needs (6,8,15)

Current research landscape – challenges

The MOGAD treatment gap

- A critical gap remains – there are currently no approved disease-modifying therapies for MOGAD, making this a major unmet clinical need and research priority
- Current management relies almost entirely on off-label use of immunosuppressants, with heterogeneous responses to therapy and resulting cycling of treatments
- Notably, many patients relapse despite B-cell depletion, suggesting distinct immunopathology compared with AQP4-NMOSD (10, 11)
- Recent comparative analyses and network meta-analyses of retrospective data suggest that intravenous immunoglobulin (IVIg) may be among the most effective maintenance therapies for preventing MOGAD relapses, followed by oral corticosteroids
- other agents like mycophenolate mofetil (MMF), azathioprine, and rituximab also show benefit, whereas MS therapies (e.g., interferon- β , natalizumab) tend to be ineffective (10)

Current research landscape – challenges

Diagnosis, disease mechanisms & health equity/access

- Misdiagnosis as multiple sclerosis (MS) remains common, leading to inappropriate treatment and potentially worse outcomes (12-14)
- For both NMOSD and MOGAD, misdiagnosis and thus delays in treatment are quite common, with one survey finding an average of 2.2 years to correctly diagnose NMOSD (6)
- The efficacy of approved NMOSD therapies in seronegative patients remains unclear and unstudied
- For MOGAD, researchers are still working to understand the pathogenicity of anti-MOG antibodies and to develop animal models that accurately recapitulate human disease (7,8,11,12)
- Multiple clinical trials are currently underway evaluating targeted therapies including anti-IL-6 receptor antibodies, anti-neonatal Fc receptor antibodies, complement inhibitors, and antigen-specific tolerization approaches, yet no therapies have yet been approved for MOGAD (8,11)
- New biologic therapies for NMOSD are expensive – outside of North America, Europe & Japan, many patients still rely on older, off-label and often less effective agents (rituximab, azathioprine, etc.), making global access and health equity in treatment major concerns

Current research landscape – challenges

Quality of life comparisons

- A 2024 multi-center study comparing quality of life in MOGAD vs. AQP4-NMOSD found that overall quality of life impairment was similarly severe in both conditions, with MOGAD patients experiencing fatigue, sleep disturbances, and depression to a degree comparable to AQP4-positive NMOSD patients
- Notably, after adjusting for pain and depression, MOG-positive patients reported worse psychological quality of life than AQP4-positive NMOSD patients in that cohort, countering any assumption that MOGAD's milder reputation translates to significantly better life quality (10)
- The take-away is that both diseases carry a high burden of both visible and invisible symptoms

Critical knowledge gaps in priority alignment

Patients and clinicians have divergent priorities on important topics

- While we now understand that clinician and patient priorities differ, four critical knowledge gaps prevent patient-centered research agenda setting
- We don't fully understand where priorities actually overlap – are there research areas that both patients and providers consider equally important? Identifying these convergence points would reveal "quick win" priorities that satisfy both stakeholder groups and could be fast-tracked for funding and implementation. The existing literature describes priorities separately but has not systematically mapped areas of agreement
- We also don't have a clear view on where priorities diverge. And where priorities differ, is it due to different time horizons (immediate vs. long-term impact), different values (cure vs. quality of life), different feasibility assessments, or lack of communication between groups? Without understanding why priorities diverge, we cannot develop strategies to bridge these gaps or make informed trade-offs in research funding decisions

Critical knowledge gaps in priority alignment

Patients and clinicians have divergent priorities on important topics

- We don't know what outcomes get lost in the gap. When research priorities are set primarily by clinical experts, which patient-important outcomes are systematically under-represented in clinical trials and funding decisions? Are there entire domains of research need—such as rehabilitation, symptom management, or psychosocial support—that fall between the cracks because they don't align with traditional biomedical research frameworks?
- We also lack systematic methods for achieving consensus across patients & clinicians – current approaches to understanding patient priorities typically rely on surveys or focus groups that capture perspectives but don't facilitate deliberation or consensus-building
- No studies have used structured consensus methods like Delphi to bring patients and providers together to systematically identify common ground and negotiate differences in research priorities for NMOSD and MOGAD
- These gaps are not merely academic—they have real-world consequences for research funding, trial design, and ultimately patient outcomes
- Research that misses outcomes important to patients may generate evidence that doesn't translate into improved care delivery or patient satisfaction
- **Addressing these questions must be a prerequisite for research funding decisions that meaningfully improve patient care**

Delphi survey – key findings

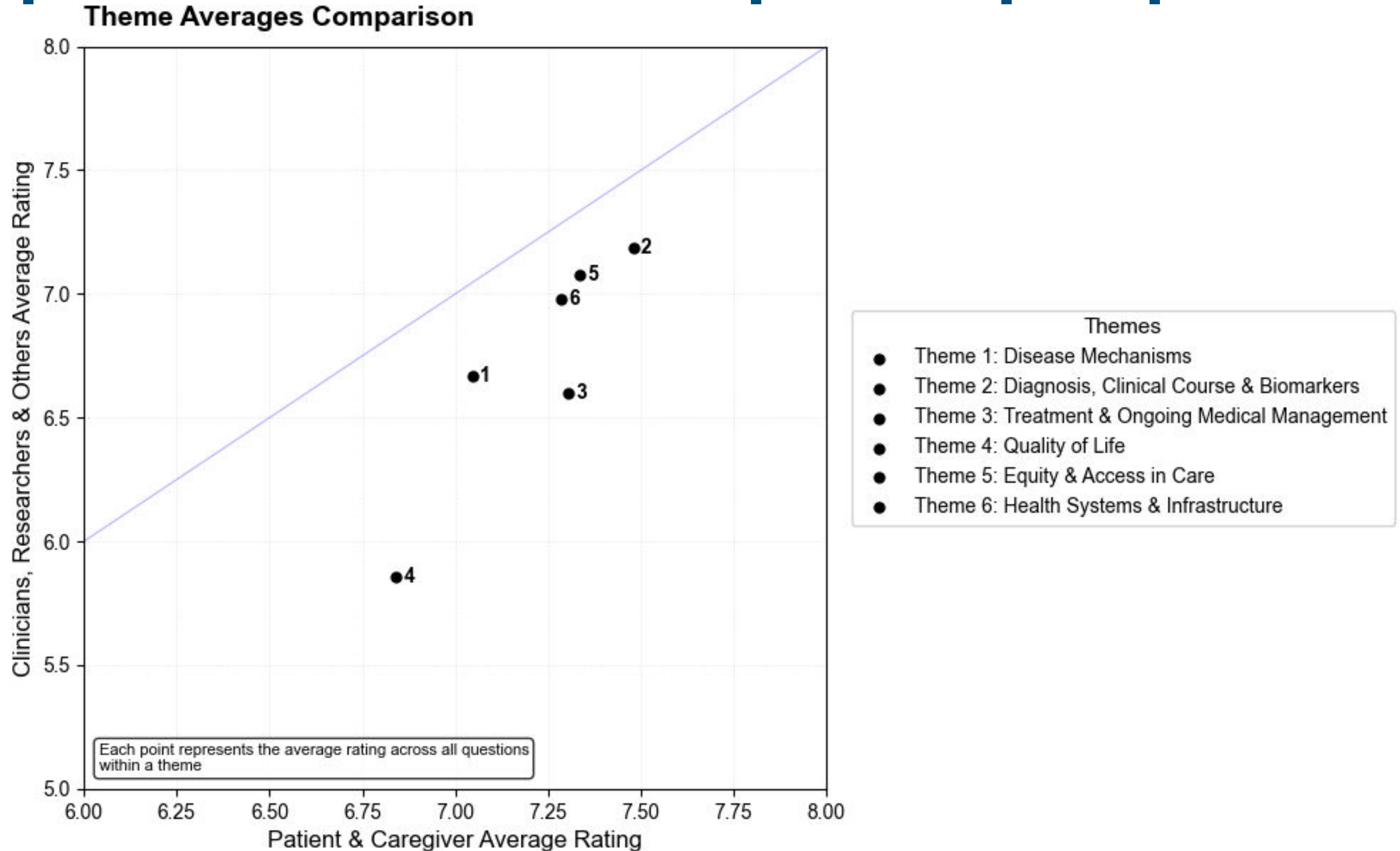
Survey design & approach

- Modified, multi-round Delphi process survey deployed
- Survey instrument developed via literature review/qualitative focus groups/expert interviews (see appendix for detailed questionnaire)
- 358 participants surveyed, with significant clinician & international representation
 - 123 patients/caregivers
 - 220 clinicians/researchers
 - 156 US/202 international
- Separate mandarin-language survey deployed in China
- Additional insights derived from shorter supplementary surveys in 18 languages, including Arabic
- **We believe this constitutes the largest & broadest survey fielded to-date within the NMOSD & MOGAD communities**

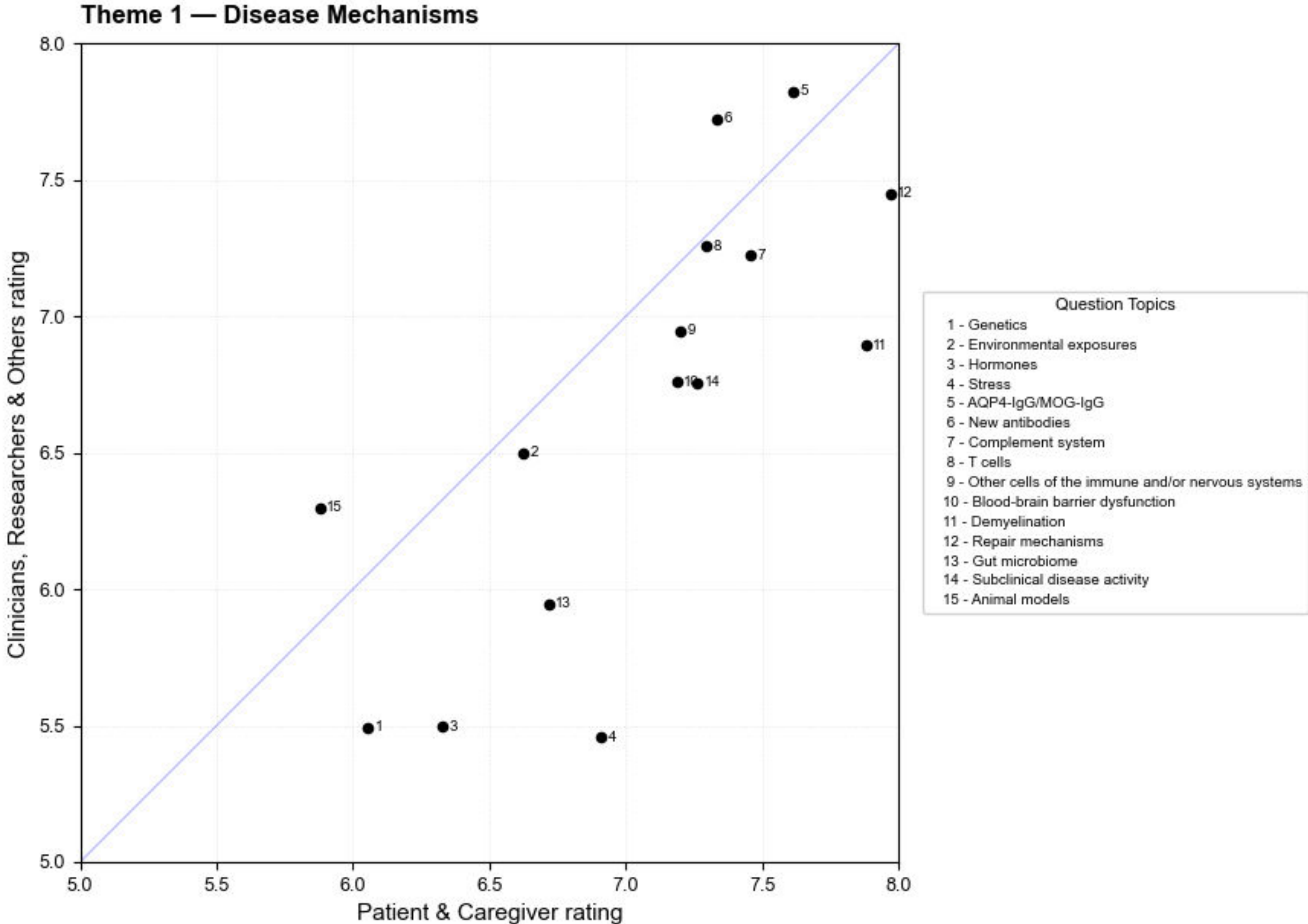
Overview of themes covered

Theme 1	Disease mechanisms
Theme 2	Diagnosis, clinical course & biomarkers
Theme 3	Treatment & ongoing medical management
Theme 4	Quality of life
Theme 5	Health equity & care access
Theme 6	Health systems & infrastructure

Theme priorities – clinician & patient perspectives



Theme 1 – disease mechanisms



Theme 1 – disease mechanisms

Summary of patient & clinician comments

Question 1 – genetics

Themes from patient/caregiver comments

- Family planning concerns
- Prevention focus
- Mixed feelings about genetic knowledge

Themes from clinician/researcher comments

- Limited genetic components identified
- Risk alleles could clarify pathogenesis
- Research priority remains moderate

Question 2 – environmental exposures

Themes from patient/caregiver comments

- Personal triggers identified
- Skepticism about finding common factors
- Unavoidable immune triggers

Themes from clinician/researcher comments

- High environmental impact expected
- Population-specific environmental factors
- Prevention potential if identified

Question 3 – role of hormones

Themes from patient/caregiver comments

- Life transition correlation
- Medication-hormone interactions
- Female predominance connection

Themes from clinician/researcher comments

- Question too broad
- Sex bias complexity
- Disease-specific relevance

Question 4 – role of stress

Themes from patient/caregiver comments

- Direct symptom correlation
- Relapse triggers
- Pre-disease emotional states

Themes from clinician/researcher comments

- Measurement challenges
- Study design critical
- Research feasibility concerns

Question 5 – role of AQP4-IgG and MOG-IgG antibodies

Themes from patient/caregiver comments

- Seronegative exclusion
- Understanding mechanism desired
- Cost concerns override science

Themes from clinician/researcher comments

- Testing capacity crisis
- Beyond MOG-IgG understanding needed
- Seronegative overlap

Question 6 – discovery of new antibodies

Themes from patient/caregiver comments

- Mental health impact
- Treatment implications
- Multifactorial disease possibility

Themes from clinician/researcher comments

- Large seronegative population
- Highest research priority
- Mixed disorder possibility

Question 7 – complement system activation

Themes from patient/caregiver comments

- Source of relapses
- Support of research direction

Themes from clinician/researcher comments

- MHC and T cell contribution
- Pathway understanding needed
- Therapeutic target potential

Question 8 – role of T cells

Themes from patient/caregiver comments

- Hope for new drugs
- Treatment focus

Themes from clinician/researcher comments

- Cross-disease therapy potential
- MHC protein involvement
- Established MS precedent

Question 9 – other immune/nervous system cells

Themes from patient/caregiver comments

- Complexity concerns
- Broad but difficult approach

Themes from clinician/researcher comments

- Therapeutic target potential
- Microglia under explored
- Cross-cell type importance

Theme 1 – disease mechanisms

Summary of patient & clinician comments

Question 10 – blood-brain barrier dysfunction

Themes from patient/caregiver comments

- Early symptom connection
- Misconceptions about affected areas
- Interest in mechanisms

Themes from clinician/researcher comments

- Limited/no comments

Question 11 – demyelination

Themes from patient/caregiver comments

- Peripheral nerve involvement
- Established understanding
- Focus on restoration

Themes from clinician/researcher comments

- Limited/no comments

Question 12 – repair mechanisms

Themes from patient/caregiver comments

- Life-changing potential in children
- Prevention vs repair priority
- Combining research questions

Themes from clinician/researcher comments

- Limited/no comments

Question 13 – gut microbiome

Themes from patient/caregiver comments

- Personal improvement experiences
- Pre-diagnosis gut issues
- Active self-experimentation

Themes from clinician/researcher comments

- Molecular mimicry identified
- Knowledge gap acknowledged
- Cross-disease research benefits

Question 14 – disease activity between attacks

Themes from patient/caregiver comments

- Silent progression concern
- Pre-attack symptoms missed
- Invisible symptoms

Themes from clinician/researcher comments

- Biomarker development crucial
- Implementation challenges
- New research direction

Question 15 – animal models

Themes from patient/caregiver comments

- Ethical concerns
- Limited understanding
- Conditional support

Themes from clinician/researcher comments

- MOG models sufficient
- MOGAD-specific needed
- Model accuracy concerns

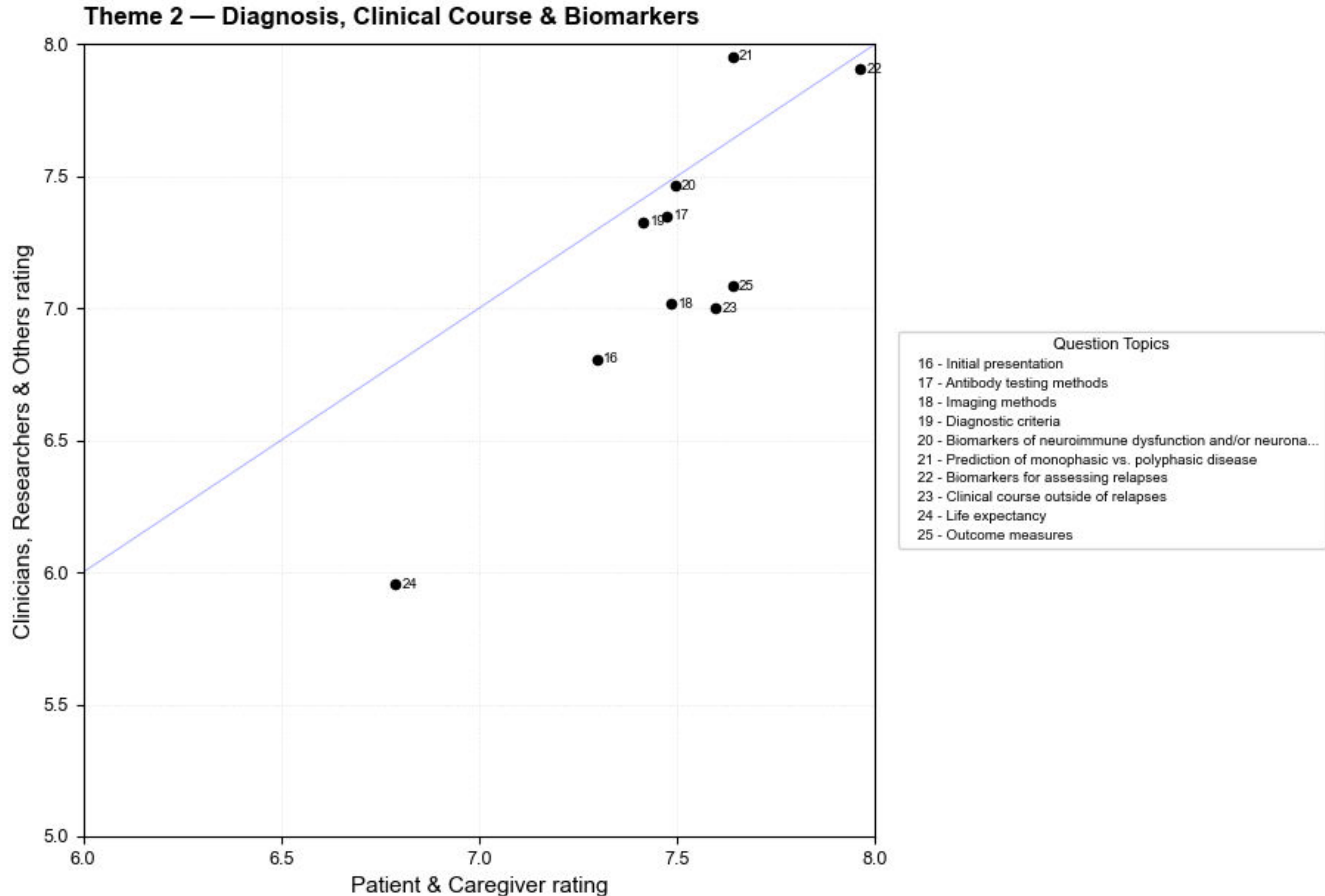
Theme 1 – disease mechanisms

Illustrative detailed comments

“This is of the highest importance to me as the caregiver to a child with lasting damage. The disease is well managed for her, but it would be life changing to reverse the damage that has caused visual impairment and brain scarring.” – patient

“Even if we can't find out why the myelin sheath is attacked, we should study how to help it recover better and faster. Prognosis is very important.” – patient

Theme 2 – diagnosis/clinical course & biomarkers



Theme 2 – diagnosis/clinical course & biomarkers

Summary of patient & clinician comments

Question 16 – variability in initial presentation

Themes from patient/caregiver comments

- Misdiagnosis trauma
- Early recognition could prevent disability
- Hearing and sensory symptoms dismissed

Themes from clinician/researcher comments

- Early identification critical
- Pediatric relevance
- Recognition education needed

Question 17 – testing variability and standards

Themes from patient/caregiver comments

- Standardization needed
- Testing accessibility
- False results concern

Themes from clinician/researcher comments

- Global testing crisis
- Need for cheaper, faster, easier tests
- Reliability vs innovation balance

Question 18 – imaging methods

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Limited/no comments

Question 19 – diagnostic criteria refinement

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Double-negative focus needed
- International effort underway
- Validation in diverse populations

Question 20 – biomarkers for multiple uses

Themes from patient/caregiver comments

- Life-changing potential
- Prevention focus
- Self-monitoring desire

Themes from clinician/researcher comments

- Disease monitoring advances
- GFAP clarification needed
- Differential diagnosis value

Question 21 – monophasic vs polyphasic disease

Themes from patient/caregiver comments

- Treatment burden concerns
- Skepticism about early determination
- Most important research area

Themes from clinician/researcher comments

- MOGAD-specific importance
- Risk stratification needed
- Watchful waiting guidance

Question 22 – true relapse vs pseudo-relapse

Themes from patient/caregiver comments

- ER visit prevention
- Personal identification strategies
- Mini-stroke possibility

Themes from clinician/researcher comments

- MRI alternative needed
- GFAP validation
- Clinical distinction challenges

Question 23 – symptom changes over time

Themes from patient/caregiver comments

- Progressive vs aging debate
- Unrecognized symptoms
- Progression without attacks

Themes from clinician/researcher comments

- Clinical course outside relapses
- Under-recognized progression
- Longitudinal studies needed

Question 24 – long-term survival

Themes from patient/caregiver comments

- Avoidance response
- Optimistic outlook
- Emotional burden

Themes from clinician/researcher comments

- Limited/no comments

Theme 2 – diagnosis/clinical course & biomarkers

Summary of patient & clinician comments

Question 25 – disability assessment tools

Themes from patient/ caregiver comments

- FND misdiagnosis issue
- Current tools inadequate
- Vision assessment gaps

Themes from clinician/ researcher comments

- Move beyond EDSS
- FDA endpoint constraints
- Existing tools could be adapted

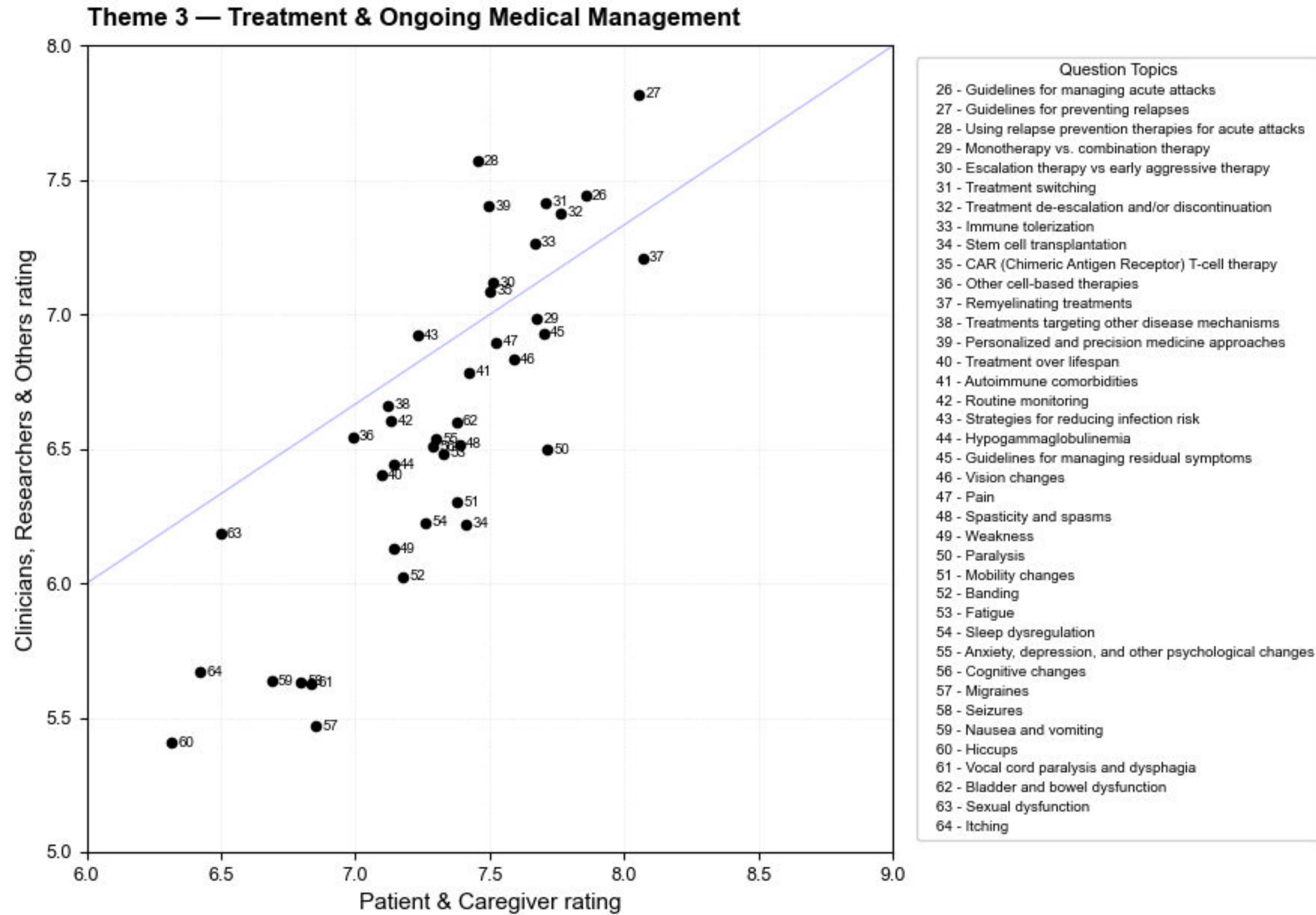
Theme 2 – diagnosis, clinical course, biomarkers

Illustrative detailed comments

**“If my initial episodes of leg tingling and weakness had been recognized as NMO, I might have avoided the loss of vision in one eye and loss of feeling from the chest down.”
– patient**

“This is very important, and limited by the fact that EDSS is so widely used, and the FDA often requires it as an endpoint.” – clinician

Theme 3 – treatment & medical management



Theme 3 – treatment & medical management

Summary of patient & clinician comments

Question 26 – acute attack management

Themes from patient/caregiver comments

- MOG vs NMO differences
- International disparities
- Evidence-based protocols wanted

Themes from clinician/researcher comments

- Prospective studies needed
- Simultaneous treatment questions
- Guidelines quality dependent on data

Question 27 – relapse prevention

Themes from patient/caregiver comments

- Treatment variation concerns
- Diet and exercise consideration
- Racial disparities noted

Themes from clinician/researcher comments

- MOGAD focus needed
- FDA approval gaps
- Population-specific responses

Question 28 – short-term use of long-term treatments

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Secondary research step
- Complement inhibitors promising
- IL-6 receptor studies possible

Question 29 – monotherapy vs combination therapy

Themes from patient/caregiver comments

- Geographic variation
- Insurance barriers
- Limited patient input

Themes from clinician/researcher comments

- Limited monotherapy success
- MOGAD priorities first
- Practical study limitations

Question 30 – escalation vs high-efficacy first

Themes from patient/caregiver comments

- Strong treatment preference
- Insurance-forced escalation harmful
- Delay causes irreversible damage

Themes from clinician/researcher comments

- Rejects MS paradigm
- Questions long-term safety concerns
- Efficacy over caution

Question 31 – treatment switching

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Limited/no comments

Question 32 – treatment tapering/discontinuation

Themes from patient/caregiver comments

- Long-term steroid concerns
- Disease-specific considerations
- Safety prioritization

Themes from clinician/researcher comments

- MOGAD vs NMOSD differences
- Older patient importance
- Lifelong treatment questioning

Question 33 – immune tolerance approaches

Themes from patient/caregiver comments

- Enthusiastic support
- Top priority for some
- Knowledge desire

Themes from clinician/researcher comments

- Limited/no comments

Question 34 – stem cell transplant

Themes from patient/caregiver comments

- Success story shared
- Skepticism about using own cells
- Fear and curiosity mix

Themes from clinician/researcher comments

- Too risky currently
- Risk-benefit calculation
- Limited clinical enthusiasm

Theme 3 – treatment & medical management

Summary of patient & clinician comments

Question 35 – CAR-T cell therapy

Themes from patient/caregiver comments

- Limited understanding
- Cautious interest

Themes from clinician/researcher comments

- Antigen-specific potential
- Disease specificity
- Technical precision recognized

Question 36 – other cell-based therapies

Themes from patient/caregiver comments

- Education barrier

Themes from clinician/researcher comments

- Limited/no comments

Question 37 – remyelinating treatments

Themes from patient/caregiver comments

- Vision recovery hope
- Volunteer willingness
- Universal support

Themes from clinician/researcher comments

- Beyond remyelination needed
- Secondary priority rationale
- Symptom-targeted approach

Question 38 – treatments targeting other mechanisms

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Conceptual confusion
- NK/NK T cell focus
- Definition needed

Question 39 – personalized treatment

Themes from patient/caregiver comments

- High priority for targeting
- System barriers recognized
- Precision medicine hope

Themes from clinician/researcher comments

- Dependent on other advances
- Complex implementation
- Future goal acknowledged

Question 40 – lifespan care considerations

Themes from patient/caregiver comments

- Aging immunity consideration
- Limited patient engagement
- Trust in clinical judgment

Themes from clinician/researcher comments

- Clinical art not research
- Not research priority
- Individual patient focus

Question 41 – multiple autoimmune conditions

Themes from patient/caregiver comments

- Universal co-occurrence
- Management complexity recognized
- Common experience

Themes from clinician/researcher comments

- NMOSD more important
- Interaction concerns
- Diagnostic challenges

Question 42 – monitoring protocols

Themes from patient/caregiver comments

- Annual MRI advocacy
- Self-monitoring apps desired
- Pain monitoring gaps

Themes from clinician/researcher comments

- Limited/no comments

Question 43 – infection prevention

Themes from patient/caregiver comments

- Vaccination timing confusion
- UTI symptom differences
- Standardization desired

Themes from clinician/researcher comments

- B-cell depletion focus
- Timing optimization needed
- Risk-benefit assessment

Theme 3 – treatment & medical management

Summary of patient & clinician comments

Question 44 – hypogammaglobulinemia

Themes from patient/caregiver comments

- Political concerns raised
- Infection risk connection
- Limited patient understanding

Themes from clinician/researcher comments

- Therapy-specific relevance
- Decreasing relevance
- MOGAD uncertainty

Question 45 – residual symptom management

Themes from patient/caregiver comments

- Research dollar prioritization
- Lack of guidance frustration
- Insurance coverage battles

Themes from clinician/researcher comments

- Limited/no comments

Question 46 – vision changes treatment

Themes from patient/caregiver comments

- Beyond optic neuritis
- Current tools insufficient
- High priority for affected

Themes from clinician/researcher comments

- Low vision tools exist
- Restoration vs management
- Technical challenges acknowledged

Question 47 – pain management

Themes from patient/caregiver comments

- Research complexity acknowledged
- Desperate for solutions
- Current medications inadequate

Themes from clinician/researcher comments

- Non-specific symptom
- Broader applicability
- Outside project scope

Question 48 – spasticity and spasms

Themes from patient/caregiver comments

- Medication failures common
- Education gaps
- Diagnostic confusion

Themes from clinician/researcher comments

- Non-specific symptom
- Lower research priority
- Clinical management focus

Question 49 – weakness management

Themes from patient/caregiver comments

- Bladder/bowel connection
- Post-diagnosis symptom
- Comorbidity confusion

Themes from clinician/researcher comments

- Generic symptom recognition
- Management over research
- Symptomatic approach

Question 50 – paralysis management

Themes from patient/caregiver comments

- Initial presentation trauma
- Rapid progression stories
- Permanent disability focus

Themes from clinician/researcher comments

- Ambitious goal
- Non-specific challenge
- Resource allocation question

Question 51 – mobility changes

Themes from patient/caregiver comments

- Gait confusion
- Rapid deterioration
- Daily impact emphasis

Themes from clinician/researcher comments

- Limited/no comments

Question 52 – banding management

Themes from patient/caregiver comments

- Unnamed symptom recognition
- Desperate for relief
- Under-recognized symptom

Themes from clinician/researcher comments

- Limited/no comments

Theme 3 – treatment & medical management

Summary of patient & clinician comments

Question 53 – fatigue management

Themes from patient/caregiver comments

- Debilitating impact
- Non-pharmacological approaches desired
- Body heaviness

Themes from clinician/researcher comments

- Limited/no comments

Question 54 – sleep dysregulation

Themes from patient/caregiver comments

- Permanent sleep loss
- Medication dependence
- Quality vs quality

Themes from clinician/researcher comments

- Limited/no comments

Question 56 – cognitive changes

Themes from patient/caregiver comments

- Personal experience confirmation
- Under-discussed symptom
- Impact acknowledgement

Themes from clinician/researcher comments

- Limited/no comments

Question 57 – migraine management

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- MOGAD-specific focus
- Disease-specific patterns
- Targeted approach needed

Question 58 – seizure management

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Disease-specific differences
- Clear disease distinction
- Targeted research needed

Question 59 – nausea and vomiting

Themes from patient/caregiver comments

- First symptom experienced
- Area postrema syndrome
- Attack indicator

Themes from clinician/researcher comments

- Effective treatment exists
- Recognition issue
- Limited research need

Question 60 – hiccups management

Themes from patient/caregiver comments

- Attack symptom recognition
- Limited concern
- Temporary issue

Themes from clinician/researcher comments

- Steroids effective
- Not chronic issue
- Lowest priority

Question 61 – vocal cord paralysis and dysphagia

Themes from patient/caregiver comments

- Specialist perspective
- Symptom prevalence
- Proactive advocacy required

Themes from clinician/researcher comments

- Limited/no comments

Question 62 – bladder and bowel dysfunction

Themes from patient/caregiver comments

- Post-treatment incontinence
- Common but undiscussed
- Quality of life impact

Themes from clinician/researcher comments

- Limited/no comments

Theme 3 – treatment & medical management

Summary of patient & clinician comments

Question 63 – sexual dysfunction

Themes from patient/ caregiver comments

- Limited/no comments

Themes from clinician/ researcher comments

- Underfunded across diseases
- Not disease-specific
- Research gap acknowledged

Question 64 – itching management

Themes from patient/ caregiver comments

- Medication reaction
- Limited patient input
- Side effect concern

Themes from clinician/ researcher comments

- Limited/no comments

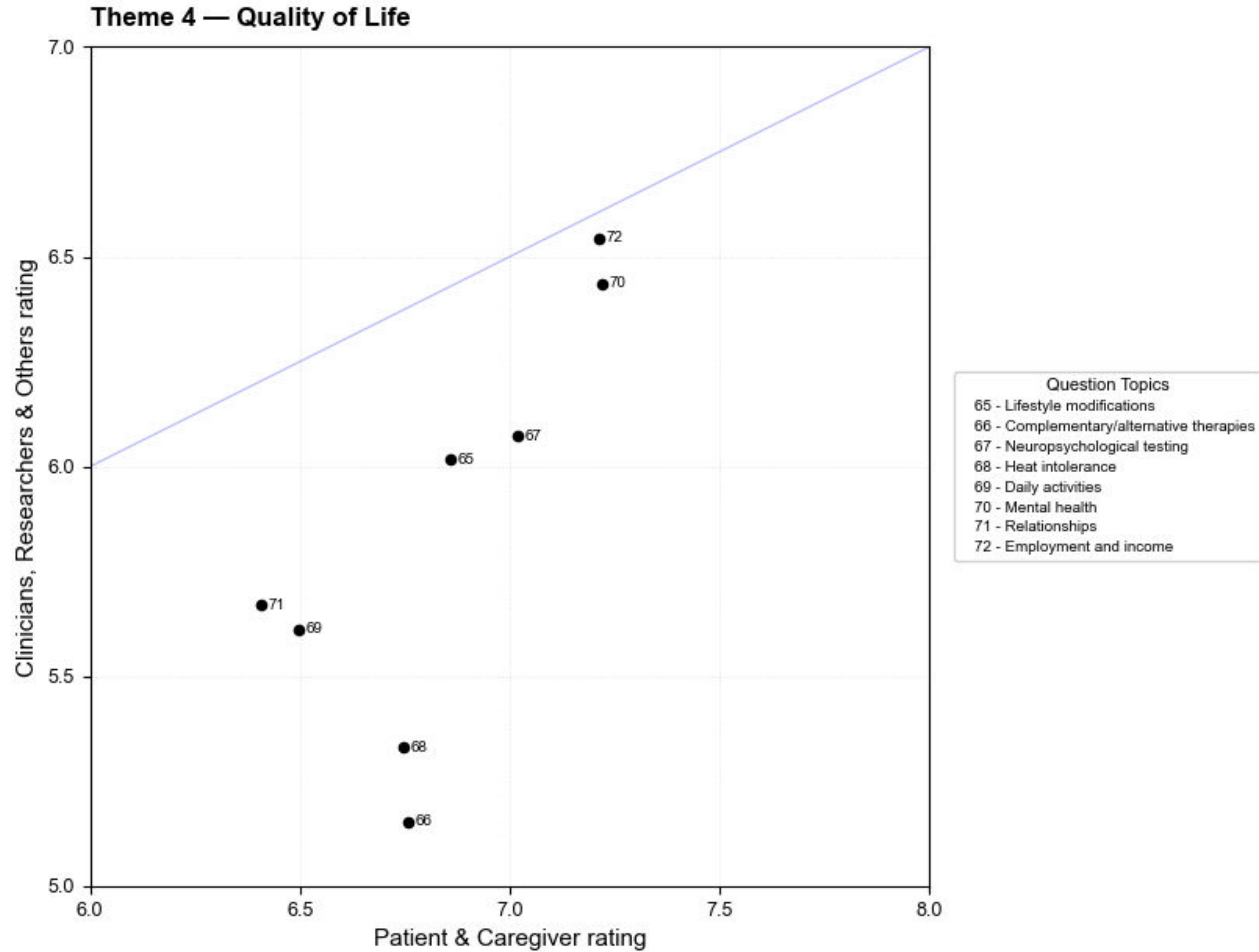
Theme 3 – treatment & medical management

Illustrative detailed comments

“[Regarding demyelinating treatments]... the possibility of recovering my sight is priceless” – patient

“Within 24 hours...my son was paralyzed from his neck down... Insurance has denied covering immunotherapy for my son.” – patient

Theme 4 – quality of life



Theme 4 – quality of life

Summary of patient & clinician comments

Question 65 – lifestyle modifications

Themes from patient/caregiver comments

- Barriers to implementation
- Individual variation
- Knowledge vs ability gap

Themes from clinician/researcher comments

- Limited research need
- Standard recommendations
- Implementation focus

Question 66 – complementary/alternative therapies

Themes from patient/caregiver comments

- Confusion expressed
- Evidence desire

Themes from clinician/researcher comments

- Limited/no comments

Question 67 – cognitive/learning support

Themes from patient/caregiver comments

- Provider expertise crucial
- Baseline establishment needed
- Early intervention importance

Themes from clinician/researcher comments

- Limited/no comments

Question 68 – heat intolerance

Themes from patient/caregiver comments

- Already established
- Management strategies exist
- Common experience

Themes from clinician/researcher comments

- Limited/no comments

Question 69 – activities of daily living

Themes from patient/caregiver comments

- Exhaustion from basics
- Work impact
- Specialist coverage

Themes from clinician/researcher comments

- Limited/no comments

Question 70 – mental health impact

Themes from patient/caregiver comments

- Strong agreement
- Critical importance recognized
- Hidden symptoms effect

Themes from clinician/researcher comments

- Limited/no comments

Question 72 – employment and income impact

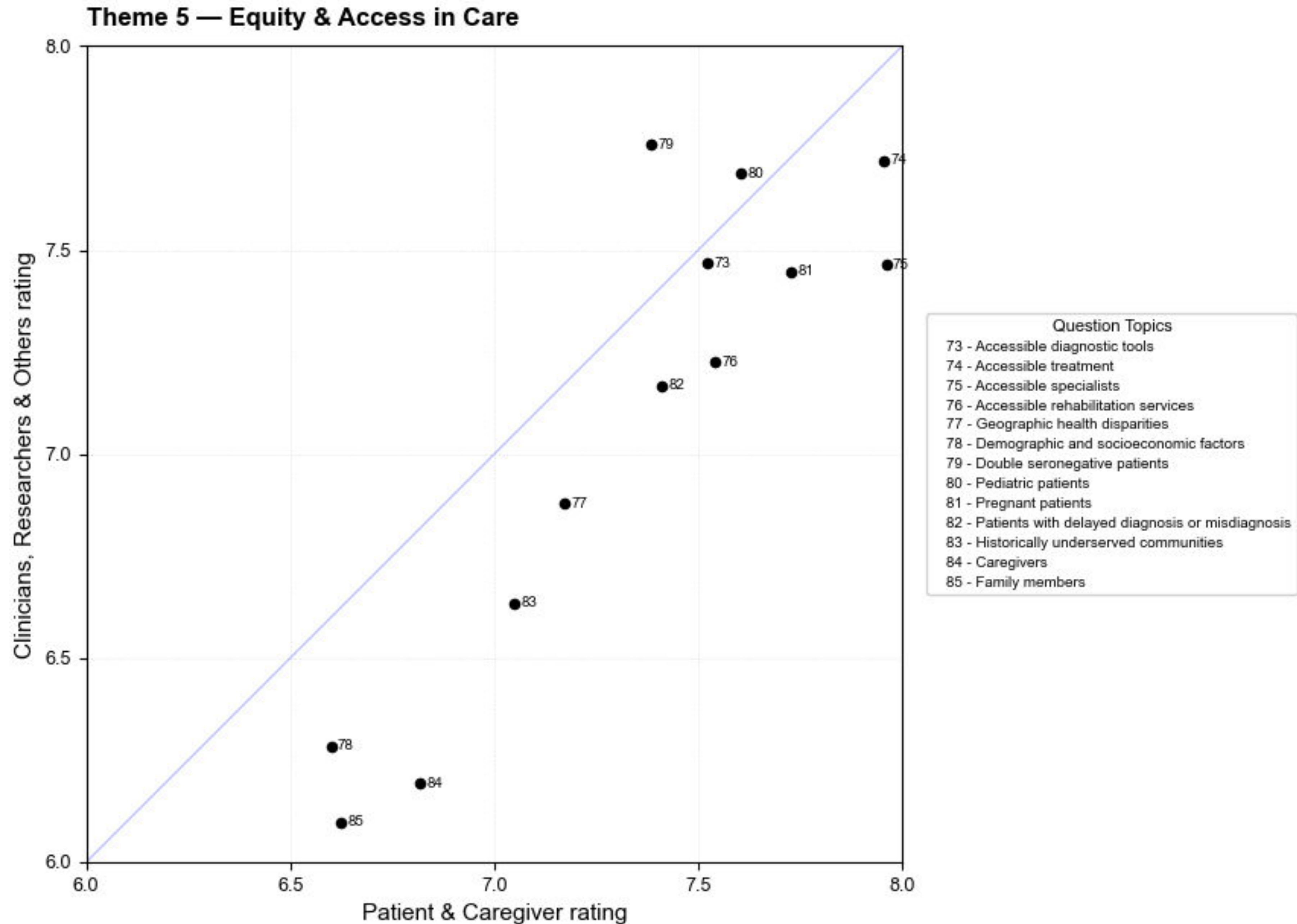
Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Economic justification
- Policy implications
- Strategic research value

Theme 5 – health equity & care access



Theme 5 – health equity & care access

Summary of patient & clinician comments

Question 74 – treatment accessibility

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Access improvement needed
- Approval expansion
- Convenience factors

Question 75 – specialist wait times

Themes from patient/caregiver comments

- Referral failures
- Delay consequences
- Multidisciplinary need

Themes from clinician/researcher comments

- Limited/no comments

Question 76 – rehabilitation services access

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Specialized expertise needed
- Disease-specific knowledge
- Training quality matters

Question 79 – double seronegative patient considerations

Themes from patient/caregiver comments

- Insurance barriers
- Research exclusion
- Limited representation

Themes from clinician/researcher comments

- Numerous unmet needs
- Research priority
- Treatment gaps

Question 81 – family planning and pregnancy

Themes from patient/caregiver comments

- Pregnancy masking symptoms
- Postpartum vulnerability
- Provider dismissiveness

Themes from clinician/researcher comments

- Limited/no comments

Question 82 – delayed/misdiagnosis support

Themes from patient/caregiver comments

- System strengthening issue
- Diagnostic journey trauma
- Equity disparities
- Lasting emotional impact

Themes from clinician/researcher comments

- Outcome documentation needed
- Misdiagnosis consequences
- Data-driven change

Question 84 – caregiver support

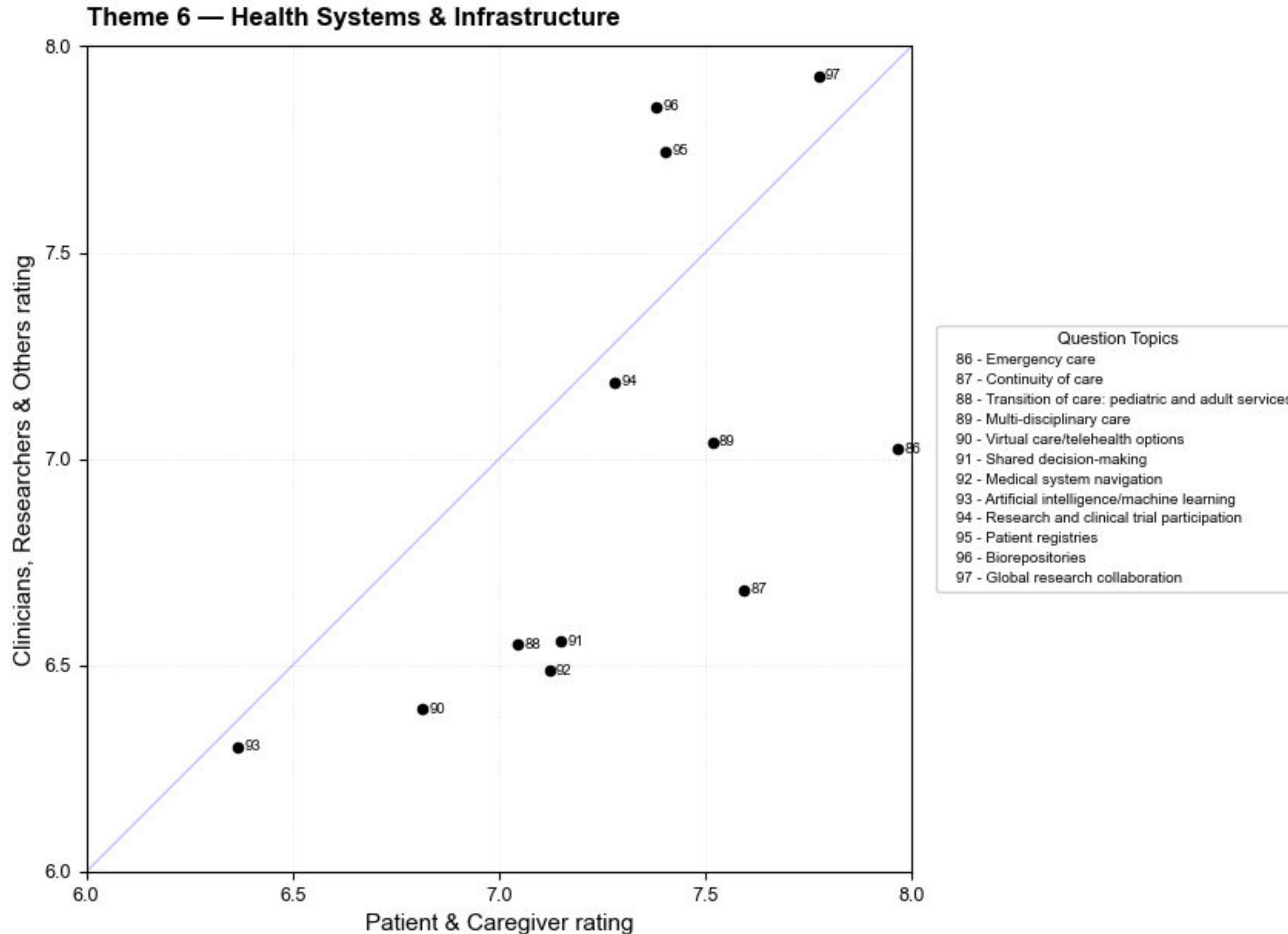
Themes from patient/caregiver comments

- Sole provider burden
- Geographic financial strain
- Well-understood but unaddressed

Themes from clinician/researcher comments

- Limited/no comments

Theme 6 – health systems & infrastructure



Theme 6 – health systems & infrastructure

Summary of patient & clinician comments

Question 86 – emergency care education

Themes from patient/caregiver comments

- Anxiety misattribution
- Provider resistance
- Critical timing failures
- Educational gap

Themes from clinician/researcher comments

- Disability prevention focus
- Front-line importance
- System-wide impact

Question 87 – care consistency

Themes from patient/caregiver comments

- Patient burden
- Transition challenges
- Legislative need

Themes from clinician/researcher comments

- Limited/no comments

Question 88 – pediatric to adult transition

Themes from patient/caregiver comments

- Similar to general transitions
- Age-specific complexity
- Critical vulnerability period

Themes from clinician/researcher comments

- Limited/no comments

Question 89 – multidisciplinary care

Themes from patient/caregiver comments

- Coordination burden
- Specialized PT needed
- Speciality versus primary gaps

Themes from clinician/researcher comments

- Knowledge sharing priority
- Structured collaboration
- Patient education integration

Question 90 – virtual care/telehealth

Themes from patient/caregiver comments

- Interstate barrier removal
- Expert access expansion
- Policy-driven solutions

Themes from clinician/researcher comments

- Limited effectiveness concerns
- Selective use criteria
- In-person preference

Question 91 – health communication quality

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- Patient input validation
- Basic clinical approach
- Insurance justification

Question 92 – patient navigation support

Themes from patient/caregiver comments

- Peer support networks
- Community-based solutions
- Existing informal systems

Themes from clinician/researcher comments

- Limited/no comments

Question 93 – AI/machine learning applications

Themes from patient/caregiver comments

- Limited/no comments

Themes from clinician/researcher comments

- OCT deep learning work
- Existing research applications
- Technology advancement

Question 94 – research participation support

Themes from patient/caregiver comments

- Participation desire
- Patient motivation
- Contributing to improvement

Themes from clinician/researcher comments

- MOGAD trial urgency
- Mechanism diversity needed
- Treatment gap focus

Theme 6 – health systems & infrastructure

Summary of patient & clinician comments

Question 96 – biorepository investment

Themes from patient/ caregiver comments

- Limited/no comments

Themes from clinician/ researcher comments

- Future research enabler
- Funding gap
- Long-term investment need

Question 97 – global research collaboration

Themes from patient/ caregiver comments

- Infrastructure foundation
- Better coordination equals better results
- Sequential development

Themes from clinician/ researcher comments

- Epidemiologic gaps
- Data foundation missing
- Multi-center requirement

Theme 6 – health systems & infrastructure

Illustrative detailed comments

“After I tested negative for MS they ruled out a neurological cause... I will always be left with the thought that severity could have been minimized.” – patient

“The hospital neurologist said ‘oh no you shouldn't have steroids’ & took me off them. I then became completely paralyzed from the waist down.” – patient

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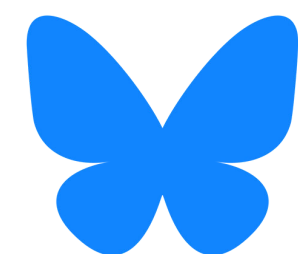
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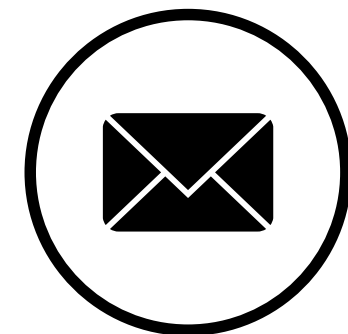
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