

Holistic and Sustainable Management of Complex Neuropsychiatric Patients

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Disclosures

Neither I nor my wife have a relevant financial relationship with a commercial interest to disclose.

Foreword

- Complexity is common in clinical neuropsychiatry.
- Recognizing and managing it improves outcomes.
- A holistic approach can improve outcomes of complex cases.
- Treatment of complex neuropsychiatric patients can be expensive and personally exhausting, and thus not *sustainable* unless managed to contain and distribute costs and burdens.
- *Medicine* is practiced by physicians (and physician extenders). (In this lecture I will call them physicians or neuropsychiatrists.)
- *Healthcare* is delivered by *organizations*.
- Diseases are managed and health is promoted by *networks of stakeholders* that include patients, families, and professionals of various disciplines.

“Trigger Warnings”

- The approach described here probably will include elements not feasible in the context of your practice.
 - It might increase your awareness of substantial work you have been doing without compensation or recognition.
 - Using only those suggestions that are feasible in your context of practice can make a difference to clinical outcomes and sustainability
- It usually more frequent and extensive communication than the standard care model, both within the treatment team and with other stakeholders. Take care that such communication is secure and HIPAA-compliant.
- Know what you need to document if you newly seek payment for work you've already been doing without compensation.
 - An increase in billing might attract attention.
 - don't want to be distracted by an audit or burdened by repeated requests for additional documentation.
- We are not going to get through this slide deck in the time allotted for this lecture. Read it at your leisure.

Elements of Sustainable Comprehensive Care

- Knowing the stakeholders and their agendas.
 - This knowledge is gained gradually, as trust is built and there are more formal and informal encounters and communications.
- Setting goals and priorities.
- Measurement-based care with research-supported outcome measures that are:
 - Seen as meaningful by the patient and other concerned parties, thus including items related to distress and to functioning.
 - Easily measured on a continual basis with minimum burden on the physician.
- Anticipating crises
- Developing a relationship network of relevant specialists
- Getting the people with money and power to understand the issues
- Knowing who's in charge of what
- Getting paid for as much of your work as is feasible in your system of care and with your patient population

Complexity Reflects Multiplicity

- Categorical diagnoses and dimensional abnormalities
- Treatments: Medications; neuromodulation, both home-based (e.g., VNS, PBM; tACS; tDCS) and facility-based (e.g., ECT, TMS, DBS); behavioral, environmental and psychotherapeutic interventions; lifestyle changes; complementary and alternative medicine
- Physicians and other healthcare professionals in both the general medical and the mental health systems
- Symptoms and signs
- Functional and cognitive impairments
- Formal and informal care providers
- Stakeholders with different agendas
- Settings of care
- Medical record systems - often not interoperable
- Cultural issues, structural issues, and social determinants of health
- Legal, environmental, institutional, and financial issues
- ICD and CPT codes (with sometimes unfortunate conversion of dimensions into categories and forced binary judgments)
- Clueless managers and executives

Profiling the Players (1)

- To manage complexity, you must know the ‘players’ (aka stakeholders or interested parties):
 - The patient him/herself
 - Family and friends who care for the patient or care about the patient
 - Others with a personal, professional, financial, or legal interest in the patient or their care
- For the patient and those who care for and/or about them, important dimensions comprise:
 - Goals and expectations
 - “Engagement” – initiative, sense of efficacy, and proactive involvement
 - Awareness of the patient’s diseases, symptoms and impairments
 - Executive cognitive function (organization, planning, self-control, self-awareness)
 - Knowledge about the patient’s illnesses and impairments and their treatments
 - Access to healthcare professionals and input to healthcare decisions

Profiling the Players (2)

- In addition to the players on the patient side, there usually are third parties behind the scenes who control access to resources and payment for them: ‘managers’ and ‘gatekeepers’ – payers, case managers, utilization reviewers, pharmaceutical benefit managers, etc.
- These third parties may not understand – or not be empowered to address - the challenges of complexity and the need to personalize treatment for complex patients.
- It is useful to identify and exchange with colleagues the usual assumptions and biases of various third parties, their most common misconceptions, and what arguments have convinced them in the past.
- Rationales for subspecialist consultations, exotic diagnostic tests, and expensive medications that have worked in the past can be worked into templates for future requests for authorization by health plans or institutions.
 - Example: Lumateperone (Caplyta) is an expensive treatment for bipolar II depression. Most health plans cover it only with prior authorization. Last month, you succeeded in quickly getting it authorized by telling the reviewer that your patient had been hospitalized twice in the past three months, that the drug is an evidence-supported alternative not yet tried, and that a year’s supply will cost much less than another hospitalization. When a similar case comes to your practice this month and prior authorization for lumateperone is needed, you pull out the template inspired by last month’s success.

Case 1: ASD, AUD, OCD, TS ...

A 25-year-old single man with high-functioning Autism Spectrum Disorder (IQ =110), Alcohol Use Disorder with binge drinking, OCD, anger outbursts, Tourette Syndrome, and asthma, lives with his parents and drives to his job as an office worker at an insurance company.

His parents have several worries:

- Non-adherence to his medication regimen. He sometimes stops taking medications as prescribed, and all his problems rapidly get worse when this happens.
- Driving while intoxicated. Several times he's driven home and looked drunk when he came through the door. They're worried about his having a crash or getting arrested.
- Potential for accidental injury when intoxicated
- Getting fired from his job for inappropriate behavior or recurrently arriving to work late
- Acts of violence against people or property
- Hospitalization for respiratory distress
- “Failure to launch” (long-term dependency on his parents as they grow older)

Case 2: MCI, Heart Failure, Recurrent Falls



Brigham and Women's Hospital
Founding Member, Mass General Brigham

A 75-year-old widow with amnestic MCI, apathy, heart failure, and several recent falls, living alone, who recently stopped leaving her home on her own because she got lost on the way home after visiting a friend. Her financial situation is precarious. Her son is worried about:

- Falls with injury.
- Medication non-adherence or unintentional medication errors leading to decompensation of heart failure and to hospitalization for that and/or other medical problems.
- Social isolation, loneliness and depression related to loss of mobility.
- Malnutrition.
- Financial victimization by scammers – or by a long-lost relative visiting his mother with “paperwork” that makes them – and not him – the heir to his mother’s remaining wealth.
- Problems related to non-payment of bills and taxes.

Case 3: Strokes, Atrial Fibrillation, Bipolar II Disorder, Type 2 Diabetes, COPD ...

A 64-year-old divorced man with two recent embolic strokes (L prefrontal and R anterior temporal), depression with mixed features, and a past diagnosis of Bipolar II Disorder, atrial fibrillation, insulin-dependent diabetes, and COPD who is still driving and managing his own affairs. His medication adherence is inconsistent. His best friend's concerns include:

- Worsening of depression leading to suicide.
- Worsening of manic symptoms with middle-of-the-night phone calls, gambling and inappropriate sexual behavior.
- Neglect or poor management of medical problems leading to hospitalization.
- Mismanaging his anticoagulants, leading to bleeding or an embolic stroke.
- Another stroke.
- A car crash – caused by existing medical problems and/or leading to new medical problems.

Initial Goals for Case 1

- Maintain employment.
- Reduce (or preferably stop) the patient's drinking. Prevent accidents and legal troubles related to drunkenness. In any case, prevent his driving while intoxicated.
- Improve social skills.
- Prevent depression.
- Reduce tics, especially vocal tics and coprolalia. The latter, which interfere with work more than motor tics, entail a risk of job loss.
- Reduce time spent on compulsions and thus prevent lateness to work.
- Prevent severe asthma attacks that typically would lead to a visit to an emergency room or urgent care clinic.

Step 1: Establish Communication, Set Goals, Reduce Risk

- Get the patient's permission to talk with his parents and his PCP.
- Make a written agreement with the patient on treatment goals.
- Mitigate the patient's risk of driving while intoxicated.
 - Have the patient carry and use an alcohol breath tester.
 - Consider an ignition interlock.
 - Periodic blood tests for phosphatidylethanol (PEth) as screen for ethanol use in past two weeks. The patient can be denied access to his car if PEth is elevated. (I have successfully used a similar strategy with a cannabis-abusing teenage patient.)
- Encourage pneumonia immunization, COVID-19 vaccination and boosters, and timely annual flu shots.
 - Enlist his mother's help in supporting immunizations if this is OK with the patient.
 - A neuropsychiatrist's concern and knowledge about a patient's general medical issues helps build trust with the patient, family, and other stakeholders.

Step 2: Simplify Drug Treatment to Facilitate Adherence

- Asthma: Once a day combination medication for prevention of attacks (e.g., steroid/beta-adrenergic agonist, or steroid/beta-adrenergic agonist/anticholinergic).
 - Make the choice in collaboration with the patient's PCP.
 - If helpful, the patient's mother can directly supervise his use of an inhaler every morning before he leaves the house.
- AUD: naltrexone injection (once a month). Acamprosate calcium (Campral) or N-acetylcysteine (NAC) can reduce alcohol craving while simultaneously reducing tics and compulsive behavior.
- Tourette Syndrome: Can explore which option (or combination) gives the best balance of benefit and side effects.
 - ER clonidine (QD dosing) or a clonidine skin patch
 - Long-acting injectable (LAI) neuroleptic.
 - A short acting version should be tried first to establish efficacy and tolerability and help with estimating the initial dose of the LAI medication.

Step 3: Rate Neuropsychiatric Outcomes: Tourette Syndrome

- Y-GTSS (Yale Global Tic Severity Scale) monthly
- Vocal tics and coprolalia rating weekly (10-point scales for frequency, impairment, distress)
 - Optimally, ratings would be collected using an app that texted the patient asking for them.
 - Initially would ask for ratings by mother, too. After comparing them would decide on the optimal reporter.
- Consideration of a wearable device for tracking tics (e.g., TicVision®)
- Y-BOCS (Yale-Brown Obsessive-Compulsive Scale) monthly.
- Weekly average of minutes spent on morning compulsions.
- Monthly count of days more than 5 minutes late to work.

Step 4: Rate General Medical and Functional Outcomes

- Asthma – using a spirometer and oximeter at home
 - FEV1 monthly, and daily during any upper respiratory infection to monitor asthma.
 - FEV1 and O₂ saturation if having an attack.
 - Count urgent care episodes and emergency room visits.
- Employment
 - Ask the patient for his periodic performance reviews from his job. This might best be done on a second or third visit, after a clinical relationship has begun.
- Health-Related Quality of Life
 - A standard measure like the SF-36 can be used, but a simpler ten-point four-dimensional ordinal scale might be sufficiently sensitive and would have obvious face value. The dimensions: (1) How good do you feel at your best? (2) How often do you feel your best? (3) How bad do you feel at your worst? (4) How often do you feel your worst?

Step 5: Increase Engagement

- Increase social support and education (collaborate with educational consultant).
 - Inform the mother about a group for parents of autistic young adults.
 - Recommend a social skills program for the patient.
- Introduce educational resources to the patient compatible with his learning style – websites, videos, etc.
- Connect with low engagement players.
 - Meet with patient's father – find out what he knows, believes and expects, and how he views his relationship with his son.
 - Assess his interest and capacity to know more and do more.
 - Listen for hints of an underlying marital problem needing attention.
 - Suggest reading and online resources if he's open to them.
- A social worker can do most of this, but the physician's participation will boost efficacy.

Scaling Up the Approach

- A neuropsychiatrist might personally implement all components of the strategy for a few patients, but except in a boutique, cash-only practice it will not be feasible to do it for everyone.
- A team including other professionals – including a psychologist, social worker, a physician extender, and a health coach – can help implement the plan once it is designed.
- Scripts and templates can be created for specific types of problems, e.g., TS with occupational interference; binge drinking of alcohol as a relevant comorbidity but not a primary problem, etc.
- Consistent use of widely understood outcome measures facilitates interprofessional communication.

Reducing Burden and Enhancing Sustainability (1): Create Virtual Teams

- Explain the sustainability concept to the patient and/or significant others (family, friends, and/or volunteer advocates).
- When significant others are committed but not engaged, take action to increase their engagement and/or bring in external assistance (coach, case manager, health educator, etc.) to motivate, educate and train *them*.
- Utilize social workers, OTs, health coaches and formal support/education/therapy groups to help the patient.
- Create a 'virtual team' including 'neuro-aware' allied health professionals, lawyers, financial planners, and educational consultants appropriate to the clinical populations you see.
- Helping professionals of other disciplines with *their* complex/difficult cases is a route to building *your* virtual team.

Reducing Burden and Enhancing Sustainability (2a): Schedule More Time and Seek Payment or Credit for It

- Make liberal use of medical visits that include counseling time (use level 3-5 E&M codes). Schedule longer and more frequent visits early in the relationship and after any major change in status or treatment.
- Use codes for non-face-to-face services that precede or follow an E&M visit (e.g., CPT codes 99417 and G2212).
- Pre-emptively schedule a 30-minute visit 2-3 weeks after the initial visit for a patient that you anticipate will be complex.
- Utilize Chronic Condition Management codes (e.g., CPT code 99490) where feasible.
- Use telemedicine service codes for telephone calls as well as video conferences - they have been more liberally covered by insurers since the start of the COVID-19 pandemic.
- Consider utilizing social workers, advanced practice nurses or physician assistants for care management activities. Their remote services often are covered by Medicare if properly documented, and an increasing number of other payers cover them.

Reducing Burden and Enhancing Sustainability (2b): Schedule More Time and Seek Payment or Credit for It

- Schedule time during your usual workday for telephone, text, patient portal, and email support of your patients. Electronic contacts should not intrude too much on your private life.
- Bill patients for your total time by the hour if feasible in your context of practice. It is sometimes possible to bill the patient at an hourly rate and supply them with itemized bills for reimbursement by their insurance plan. The bills often will require use of exotic CPT codes to fully describe services rendered.
 - Hourly billing with post-hoc reimbursement of covered services is not possible in all cases; sometimes accepting the patient's insurance will preclude it. Billing for services not covered at all by the patient's insurance sometimes is feasible. The patient's informed consent should be sought prior to initiating atypical billing.
- Stay familiar with Medicare rules for coding, documenting and billing complex medical management and care coordination in various settings – or identify some wonky person in your organization who makes a hobby of being up to date on the latest from CMS.
- If working in a group practice or academic setting, an administrative staff person might assist with conceiving and implementing an effective coding and documentation strategy.

Reducing Burden and Enhancing Sustainability (2c): Schedule More Time and Seek Payment or Credit for It

- Extra time with complex outpatients can prevent hospitalizations and ER visits and reduce overall healthcare costs and total physician time. This can reduce burnout.
 - Replacing a neurologist or psychiatrist who quits because of burnout can be very expensive to a clinic, group practice, or health system. An empty position does not generate 'top line revenue'.
- In a large system this offset of time and costs might be demonstrated quantitatively by having some clinics implement an unconventional scheduling and coding/billing policy while others give care as usual. Clinical, human resources, and financial outcomes would then be tracked, aggregated, and compared.
- The three strongest arguments for comprehensive and holistic care are better clinical outcomes, greater cost-efficiency, and prevention of clinician burnout. Sustainability with colleagues requires convincing them of the first and the third. Sustainability with hospital/clinic management and payers/managed care organizations requires convincing them of the second.

A Big But: Two (or More) Sets of Books

- Comprehensive care delivered in a resource intensive way by one organizational unit might yield the greatest benefits for a different unit.
- For example, comprehensive neuropsychiatric care (aka “behavioral health”) often prevents hospitalizations for general medical conditions.
- If general medical care and mental health care costs are accounted separately, cost savings from comprehensive neuropsychiatric care might go unrecognized or might be not be properly attributed.
- Separate accounting for outpatient, inpatient, and emergency services, and for costs and revenues by department, can make it even harder to give credit where credit is due.
- Solutions to these challenges require dedicated efforts by people with administrative and/or health services research backgrounds. In a healthy organization, the cost effectiveness of comprehensive neuropsychiatric care only needs to be proved occasionally rather than continuously.

Sub-subspecialize (Sub²-specialize) for Sustainability

- Your practice of ‘neuropsychiatric primary care’ should specialize in a small number of specific neuropsychiatric conditions or syndromes.
- Become expert in managing these conditions, including:
 - Recognizing and managing their common comorbidities and complications.
 - Evaluating and mitigating their functional impact.
 - Understanding and dealing with legal, regulatory, administrative, and financial issues associated with the conditions, e.g.,
 - Eligibility criteria for disability payments or specialized publicly-funded services.
 - Payers’ typical prior authorization requirements for expensive medications, devices, or diagnostic tests; for invasive procedures; for inpatient care, etc.
 - The most useful and least controversial CPT codes for extra time you spend – considering the patients’ primary diagnoses and most common payers.
- Your *consultative* practice may be broad, but the range of cases in which you are the “CEO” and principal provider of continuing care usually should be much narrower. For example, you might limit your sub²-specialty practice to one half-day per week.

Things to Know About Your Sub-specialty and the Patients You See Most Often (1)

- Typical illness narratives –adjusted for cultures or subcultures if applicable
- Usual comorbidities and complications
- Usual reasons for emergency care
- Usual causes of adverse outcomes
- Functional concerns and options for optimizing function, including potential roles for OTs, PTs, speech therapists, and educational specialists.
- Wearable devices and ‘connected health’ tools and services potentially helpful with the clinical population
- Most valid, least burdensome rating scales for disease severity and for common symptoms, comorbidities, and functional impairments
- Emerging treatments, including complementary and alternative treatments
- Ongoing clinical trials, especially those with the option of local participation

Things to Know About Your Sub-specialty and the Patients You See Most Often (2)

- Complementary and alternative treatments relevant to the patient population, including the status of evidence for their efficacy and safety, and reliable, qualified, and ethical providers of the associated services (e.g., acupuncture) and/or goods (e.g., herbs, vitamins, essential oils).
- Potentially relevant 'brain hacks', e.g., transcranial AC or DC stimulation (tACS or tDCS); vagus nerve stimulation; photobiomodulation (PBM); bright light therapy; biofeedback. This includes knowing suitable sources of OTC (FDA cleared but not FDA approved) devices.
- Lifestyle issues relevant to the condition (e.g., sleep/wake schedule, diet, physical environment, working conditions).
- Administrative policies of hospitals, agencies, and payers.
- Educational materials (publications and websites) for patients and patient-side players.
- Local resources, both clinical and supportive.
- Support and advocacy groups (in person and online) for patients and patient-side players.

Generic Goals of Neuropsychiatric Care

- Optimizing survival, function, and quality of life.
- Minimizing disability, pain and suffering.
- Promoting healthy cognitive, emotional and social development in child, adolescent and young adult patients. This includes helping patients find appropriate educational opportunities and make the most of them.
- Promoting occupational productivity, satisfying relationships and personal fulfillment in working-age adults.
- Enabling people with children, or who wish to have children, to be happy and good parents.
- Promoting adaptation to aging and age-associated diseases and conditions and enhancing the meaning of life for older patients.
- For patients of all ages, protecting them from abuse, neglect, and/or exploitation.
- For patients of all ages, preventing diseases and injuries to which patients' pre-existing conditions make them especially vulnerable.

Sustainability Should Not Depend on Masochists, Saints or Clinical Superheroes (The Supply is Limited)

- Emotional, financial, and time burdens of care for *all* caregivers – including physicians – must be recognized and taken seriously. Burdens should be shared among clinicians and other patient-side players to make care *sustainable* and not dependent on anyone being (consistently) masochistic or self-sacrificing.
- Comprehensive care planning for a complex patient should include consideration of who bears which burdens and each player's capacities and resources.
- Clinicians should get paid fairly, enjoy their work, stay healthy and not burn out.
 - Making this happen in large healthcare systems, academic medical centers and group practices is non-trivial. Care of complex patients contributes disproportionately to burnout and is a common context for hard work that is poorly paid. Improving the focus and structure for care of complex patients can make a difference to the overall sustainability of a clinical practice.

Actively Managing Complexity Improves Sustainability

- *Relational sustainability*: Optimizing satisfaction, minimizing burden, reducing interpersonal conflicts and preventing stress-related illnesses for the patient-side players.
- *Professional sustainability*: Preserving the health, morale and productivity of the physicians and other healthcare professionals involved; keeping skills and knowledge up to date.
- *Financial sustainability*: In most healthcare systems this will require demonstration of cost offsets, i.e., translating the neuropsychiatrist's longer visits, conferences with other players, teamwork and electronic communications into fewer hospitalizations, fewer episodes of urgent care, a lower frequency of visits with other specialists, and lesser use of unnecessary tests and procedures.
 - Proving cost-offsets isn't necessary in an independent, all-cash/hourly rate practice.
 - In a hard-core managed care context, proving cost offsets or cost effectiveness is essential for supporting organizational change – but admittedly difficult.
 - It can be feasible in an academic medical system when there are people on the staff or at an affiliated health services research center who are already doing outcomes and cost-effectiveness research using data from the system.

Contemporary Challenges to Implementation

- Administrative and financial separation of ‘mental’ or ‘behavioral’ health care from general medical care, and of outpatient from inpatient care, imply barriers and financial disincentives for integrating care.
- The terms ‘mental’ and ‘behavioral’ are stigmatized and the word ‘carveout’ has dark connotations.
- The design of electronic medical records can make complexity more difficult to manage. Even ordinary patients can accumulate dozens of conditions in an electronic medical record, which can make it hard to isolate the conditions that matter the most, and to recognize when complexity requires sub-subspecialized management.
- The future promises AI-based review of EMRs that will identify patients for whom atypical comprehensive holistic neuropsychiatric care is cost-effective as well as clinically and morally right. Similar geeky technology will generate estimates of the total expense of comprehensive holistic care along with estimates of money saved by providing it.

More About Electronic Medical Records: Problems of Epic Proportions

- They usually have no standard place for strategic summaries and for inclusion of rating scales selected to fit with patients' clinical issues and the communication styles of individual patients and/or caregivers.
- There usually is no place to aggregate data from consumer medical devices such as wearable sleep and activity trackers.
- EMRs from different healthcare systems are not fully interoperable.
- From a clinician's viewpoint, EMRs focus excessively on routine documentation for administrative or legal purposes.
- Subspecialty- and condition-specific templates for EMRs can help. The IT support team for an organization's EMR sometimes can help with designing and/or implementing them.
- Electronic medical records in their usual implementations have no standard place for presenting a thoughtful précis of a patient's course of illness, for specifying treatment strategy (as opposed to specific medical orders or prescriptions) or for displaying a patient-specific 'instrument panel' or 'dashboard'.
- A potential partial solution is the construction of patient-specific 'disease narratives' that are then included in the EMR. Any clinician encountering the patient can quickly read the narrative and immediately see the patient from a comprehensive neuropsychiatric viewpoint.

The 'Disease Narrative'

- After a comprehensive evaluation of a patient, a neuropsychiatrist can create a 'disease narrative' that provides a holistic view of a patient's condition, including a history of the condition's onset and progression, and identifying unresolved diagnostic questions, opportunities for improving treatment, practical and useful outcome measures, risks to be managed, and issues related to family, education, and work.
- The narrative is first discussed with the patient and/or other patient-side players and is then tweaked to incorporate their concerns.
- It is then shared with other players both on the patient side and on the clinician side.
- A sample narrative is provided in the course syllabus as an appendix to this presentation. In my experience a narrative can empower patients and those who care about them to make the system work better for them.
- Creation of disease narratives can be paid for via E&M codes, because the discussion of a draft narrative can be the primary content of a special patient visit.

An Email That Made My Day

- In my experience, patients greatly appreciate disease narratives. Such documents can help them get the care they need in a sometimes-chaotic system of care.
- A few weeks ago, I received an email from a patient that made my day.
 - The patient is a French chef disabled by a combination of sub-optimally treated conditions including complex partial epilepsy, obstructive sleep apnea, ADHD, and migraine.
 - I had created a disease narrative for her that opened doors at other doctors' offices – e.g., got her long-term EEG monitoring to finally nail down why her epilepsy interfered so much with her work, and got an ENT specialist to take a second look at potential surgical treatment of her OSA – a condition that had been minimized because she is slim and not obese.

“Thanks doc, I know I’m paying you for it, but I really appreciate your focus - you’re literally the first doctor who I’ve ever felt heard by. Your positive outlook gives me hope for the first time in a long time.”

A Recap of the Basics (1)

- Fully identify the players and their roles and competencies
 - Is there a 'CEO'? Is there a 'virtual team' recognized by all involved professionals, or are some of the clinical players peripheral and not aware of what others are doing?
 - Whose opinion counts the most among the patient-side players?
 - Who is on the front line of response for each of the most likely urgent or emergent situations?
 - What are various people's expectations?
 - What is each person's level of commitment, engagement, knowledge, and executive function?
- Define your own role and then try to ensure that all (or at least most) of the players see your role the same way as you do.
Are you:
 - A diagnostic consultant?
 - Provider of an Nth opinion?
 - Provider of a specialized diagnostic or therapeutic service?
 - Treatment strategist?
 - CEO?
- Know when other players on either side don't share your view of your role.

A Recap of the Basics (2)

- If you are the CEO or the strategist, determine (or recommend) the goals of treatment, and try to align other clinicians and the patient-side players with those goals.
 - Patient-side players might include any combination of family members, friends, paid caregivers, and advisors.
 - There might be a physician or psychotherapist who has a long-term and influential relationship with the patient or a significant other.
 - Payers and case managers might have a role.
 - The process of alignment usually is gradual. It can be facilitated by a patient-side player who is on board with the plan and has positive relationships with relevant people.
 - A comprehensive disease narrative that is endorsed by the patient and/or the patient's spouse, parent, or adult child can be a useful tool.
- Determine what needs to be measured periodically, in what way, how frequently, and by whom.
- Always consider the burden of measurement – convenience and affordability are critical for long-term consistency. Data from mobile devices and smartphone apps – “connected health” – often are superior to printed questionnaires. A combination of data from wearables and simple ordinal self-ratings often does the job.

What is the Time Budget?

- How frequently will you (or other clinician(s) you advise or supervise) need to update knowledge of the patient's status?
- How frequently will the CEO or strategic consultant need to talk with and/or talk about the patient?
 - For how long?
 - In person, by teleconference, by phone, by secure email, or by text?
- What is the time budget for front-line care providers – both formal and informal?
- How much time will be needed to coordinate care?
- Time budgets and money budgets both matter. Often, money alone can't buy what a patient needs.

Defining Requirements: Components of an Instrument Panel / Dashboard (1)

- Identify the full problem list and match each problem with the responsible person(s) – identifying gaps and who will be responsible for filling them. Clarify legal issues like advance directives and healthcare powers of attorney.
- Select a way to measure the status of each problem.
 - Neuropsychiatric rating scales: Measures of cognition, mood, behavior, apathy, etc.
 - The choice of scale should consider the primary diagnosis, the setting of care, and the patient's baseline. For examples, a scale for depression in people with epilepsy may work better than a PHQ-9 in a patient with epilepsy.
 - Issues of personality and culture might make one measure better than another. For example, some people do better rating frequency of symptoms rather than severity. Others are better at noting the absence of the positive rather than the presence of the negative. Some patients focus on somatic complaints, while others focus on their emotions.
 - Functional assessments: ADL, IADL, etc.
 - Include specialized assessments like financial capacity and driving ability when these are critical input to major life decisions.

Defining Requirements: Components of an Instrument Panel / Dashboard (2)

- Use disease-specific rating scales, e.g., those for specific movement disorders.
- Track system-specific physiological measures, e.g., O_2 saturation and FEV_1 for patients with COPD and other respiratory conditions – especially those that can be done at home by the patient or family, with affordable devices such as glucometers, peak respiratory flow meters, and automated BP cuffs, Recording and tracking should be automated when possible.
 - A wearable glucose monitor linked to a smartphone can enable better control of diabetes.
- Home-based and point-of-care measurement is getting better all the time.
 - Blood alcohol level and blood glucose level, for example.
- 24-hour sleep and activity tracking with an Oura, Fitbit, Whoop or similar device provides insights useful in treating a wide range of conditions.
 - Getting online access to a patient's data can be complicated, and in the worst case, the patient or a family member can send screen shots to the clinician.

Get It Right, Then Make It Simple

- Once you know which standard rating scales or rating scale items are most sensitive and specific for your patient's issues, you can put together briefer, individualized scales for tracking your patient's progress.
- Patient-side players can be asked to suggest rating scales or questionnaires if there's reason to think they are familiar with one or more. For example, people active in disease-specific advocacy organizations often know about scales to measure their condition of interest.
- Unless you're planning to publish a case report, there is no need to have a patient fill out every item on a rating scale. If a patient has never had a symptom there may be no reason to have them rate that symptom repeatedly.

Work Product: A Written Strategy

- A strategic plan begins with a summary of 1-2 paragraphs that captures the big picture of who the patient is, the goals of treatment, their present condition, the biggest challenges, what needs to be done first, and the greatest risks.
- The summary is followed by a comprehensive written action plan.
- A strategic plan can be completed in the clinic, in the presence of the patient and/or family, as part of a recognized, schedule, coded, and compensated healthcare service. (Getting paid for documenting strategic plans helps with sustainability.)
- Developing a written strategy in the clinic with patient and/or caregiver participation can be a billable E&M service, where the preparation and discussion of the strategy is the ‘counseling’ component.
- It might be feasible to schedule in advance a 30-to-60-minute E&M visit – in-person or remote – entirely devoted to constructing and discussing a strategy and its implementation.
- Whether a patient needs a detailed ‘disease narrative’ or just a treatment strategy depends not only on how unusual or complex the case is, but also on the extent of unresolved questions, conflict among patient-side players, disagreement among clinicians, and/or patient-side unhappiness about the processes and outcomes of treatment to date.

Questions for the Strategist (1)

- Is someone in charge of coordinating care? Is *anyone* in charge? Is more than one person trying to be the care coordinator? If more than one, are all would-be coordinators on the same page?
- Is there someone on the patient side who has the ‘right stuff’ and should be more involved? Would that be OK with the patient? How should the person on the patient’s side with optimal knowledge, skills, and attitudes be asked to participate (more) in the patient’s care? What additional education or training might be helpful to them?
- Should any different/additional providers be involved?
- Should the site of care change?
- What additional diagnostic information is needed?
- What additional therapies should be implemented?

Questions for the Strategist (2)

- What measures should be used? How frequently should they be repeated? Who will collect the data? Is there a role for devices in collecting the data?
- What are the routine and the urgent communication channels?
- How frequently will there be scheduled communication?
- When and how should the patient or caregiver be in touch with clinicians between scheduled encounters?
- How could “connected health” (wearables, connected devices like Wi-Fi linked medication boxes, and smartphone apps) make monitoring easier, promote adherence to prescriptions, aid in diagnosis, and/or facilitate personalization of treatments?
- Who will be prescribing medications for each of the patient’s diagnoses that requires drug treatment?
- More generally, who’s going to do what? Is some form of group dialogue needed? Who should be on a patient-specific, secure email distribution list?

Who Will Coordinate Clinical Care?

- Consider the patient's and/or other caregivers' knowledge, engagement, commitment and executive function.
- If all of these are sufficient, coordination by the patient and/or a significant other approved by the patient, with sharing of decision-making between physicians, the patient, and the designated coordinator, is clinically sound, cost-effective, and usually sustainable.
- If a key ingredient is missing, consider whether it can be added (e.g., with education, motivational interviewing, or a support group), or whether an alternate coordinator can be found who is acceptable to the patient.
- Be alert to unrealistic or masochistic (though well-meaning) offers to coordinate care by people who deeply care about the patient but underestimate how much knowledge, effort, and/or time will be involved.
- It is usually better to have the patient or significant other, *if qualified*, to be the primary coordinator of care, rather than a professional case manager. A person of average intelligence and secondary education, with no clinical training, can learn a lot about a handful of conditions and a short list of medications. (By contrast, clinicians must learn about – and stay up to date on – hundreds of conditions and treatments.)

Dashboards and Instrument Panels

- ‘Dashboards’ or ‘Instrument panels’ can be paper documents with a structured format, pages in an EMR, Web pages with discrete windows or “widgets”, Google Docs, or templates for email or text messages. If using a cloud service, make sure you use a strong password and, ideally, two-factor authentication.
- The panel has a zone for each problem or therapeutic objective.
- What’s in each zone:
 - The most recent measures of the condition or disease, including measures of symptoms and function, and disease-related biochemical and physiological biomarkers - including data from wearable devices.
 - What treatments are being given
 - Who’s in charge of addressing the problem or pursuing the goal
 - When the status of the issue was last updated
- Another zone lists the players, their roles, their contact information, and any special warnings or alerts.

Anticipate Urgent Problems and Prevent Unnecessary Emergencies

- Each patient's combination of diseases, conditions, impairments, clinical risk factors, treatments, living arrangements, etc. enables prediction of the most likely acute problems. Some will inevitably be emergencies. Some will not be emergencies if they are promptly recognized and appropriately handled.
- For each of these risks, the strategic plan suggests:
 - Prevention
 - Early identification (how and by whom)
 - By the patient, from symptoms.
 - By others, from signs or patient complaints.
 - By either, using devices or measurements.
 - Who will respond (and in what way)
 - Patient or other patient-side players.
 - Healthcare professionals.

The Role of Devices, Apps, and Home Test Kits(1)

- Proactive follow-up and patient engagement are the most active ingredients in effective chronic disease management. Devices add to this but don't substitute for it.
- Devices and smartphone apps are most useful when they measure things the patient can't self-report or that would be difficult to integrate over time, e.g., sleep efficiency; diurnal variation in physical activity; respiratory peak flow; O₂ saturation; smartphone EKG rhythm strips of someone with a history of atrial fibrillation; post-ictal headphone-style personal EEG recordings from someone with a mixture of epileptic seizures and PNES.
- The range of phenomena measurable with mobile devices and smartphone apps grows continually. Smartphones with apps (and sometimes also a smartwatch or other wearable) can estimate sleep parameters and analyze complex tremors. Wearables can record physiologic changes that precede seizures. Precise measurement and automated recording of blood alcohol levels can be accomplished with a matchbook-sized device. Blood sugar can be continually checked via a subcutaneous sensors on a wearable device linked to a smartphone.
- A home urine test for THC metabolites has proved useful in my practice for managing patients with problematic cannabis use. Similar home urine tests are available for cocaine, opiates, and amphetamines, and purchased in bulk they cost less than \$2 each.

The Role of Devices and Apps (2)

- Anyone with the potential for becoming lost can be tracked – and can quickly and easily summon help – with an iPhone.
- Driving behavior can be tracked using a ‘black box’ in the car.
- Internet-connected pill dispensers can help people with mild cognitive impairment who have mild-to-moderate impairment of executive function but relatively intact praxis.
- Home monitoring cameras and applications can be used by family or friends to monitor patients with MCI or mild dementia who are living alone or with a cognitively impaired spouse. Aosu makes a line of easily configured automated security cameras that detect and follow movement, can be remotely operated over the Internet, and include a two-way speakerphone. Google Nest has a similar line of products.
- Higher-functioning patients can benefit greatly from discussing their data with their physician. For example, patients can continually track sleep and activity with an Oura ring, and review of the data can help a patient learn about the relationship of nighttime sleep quality, sleep timing, and daytime activity. This can prompt their consistent adoption of better sleep hygiene.
- Sharing measurements with patients can help overcome denial and can reduce patients’ self-stigma.

Patient and Family Engagement

- Engagement of patients and their family members (and/or friends) is a critical factor in effective care of a functionally-impaired or medically vulnerable patient's care.
- Highly engaged individuals will seek your help. Your goal with them is educate, to manage demand and to distribute burden.
- Low-engagement people need outreach, clinician-initiated contacts, and coaching or motivational interviewing to increase their level of engagement.
- If no patient-side player can be an informal case manager, a professional or trained volunteer might be needed to be a patient advocate and/or case manager.
- Standardized measures of patient and caregiver engagement are available (e.g., the Patient Activation Measure). They have established relationships to care outcomes.
- Motivational interviewing and groups for support and education are two ways to build engagement. Distress over a patient's illness sometimes can be translated into increased engagement in the patient's care and willingness to be educated and to become proactive.
- Disease-specific organizations/advocacy groups can be resources for engagement, education, and activation.

Align Goals and Treatments with Patient and Family Beliefs when Feasible and Appropriate



Brigham and Women's Hospital
Founding Member, Mass General Brigham

- Patients and families may have beliefs and convictions – sometimes related to their cultural background – that give greater importance to certain goals of treatment and lesser importance to others, stigmatize certain diagnoses and symptoms, conceptualize diagnoses in a distinctive way, or favor or oppose specific types of treatment. Examples include:
 - Viewing some form of higher education as critical regardless of a child's inclinations or cognitive capacities.
 - Stigmatizing (the diagnosis of) depression but not stigmatizing a sleep disorder, chronic pain or chronic fatigue.
 - Preferring nutritional supplements, acupuncture, therapeutic exercise, herbs or consumer devices (e.g., light boxes) to drugs or psychotherapy.
 - Preferring to receive prescriptions for psychotropic drugs from a primary care physician rather than a psychiatrist.
 - Regarding it as 'addiction' or 'dependence' to continue an antidepressant for months after depression has improved.
 - Ruling out any medication that has potential adverse effects on sexual function.
- Beliefs like these can undermine acceptance of diagnoses and adherence to treatment if they're not known and addressed.
- Sometimes accommodation of patient and family beliefs is feasible, sometimes it's not. Getting agreement on how to measure the most important outcomes of treatment can be a good starting place for identifying culturally-distinctive perspectives on the patient's illness and its treatment.

Work-Related Concerns

- Keeping a patient working – if their illnesses permit – is a high priority unless that patient is truly ready to retire or would clearly be disabled even with accommodations or a realistic change in their job.
- A focus on the patient's work – impediments, solutions, and adaptations – sometimes brings a disparate group of concerned people together.
- Occupations – from physicians to airline pilots – have rules that may have adverse consequences for people who receive a specific diagnoses or treatment.
 - For example, a depressed airline pilot might lose their medical clearance to fly commercially if his depression is treated with venlafaxine but not if it is treated with fluoxetine.
- It's important to know about relevant rules and regulations – both highly specific job-demands and 'institutional stigma' - to avoid unnecessary disruption of the patient's work if there is not in fact an occupationally-relevant impairment of function.
- Know when a realistic, feasible accommodation would help a person continue working successfully – and how to counsel the patient on effectively seeking such accommodation. And when counseling should focus on retiring from work that is no longer appropriate. “Better to retire with honor than to be fired in disgrace.”

Complementary, Alternative, and Integrative Medicine (CAIM)



- Patients' and families' wishes to use complementary and alternative treatments should be accommodated when feasible - but not when the desired treatments are known to be harmful (or potentially harmful), or when standard allopathic care is supported by good evidence and is highly efficacious, readily available, and doesn't have risks unacceptable to the patient.
- A patient's preferring an alternative treatment to an SSRI for MDD of moderate severity is reasonable. SSRI antidepressants aren't for everyone, and there are alternative treatments with similar efficacy and support from published clinical trials.
- Apparently benign alternative or complementary treatments may be given when the patient wants them, when they are not incompatible with conventional best practice, and when there is published evidence of efficacy (not necessarily a randomized controlled trial) or credible preclinical science supporting a plausible rationale for their efficacy.
- Monitoring effects of alternative treatments with biomarkers, performance tests, or other objective measures can convert a patient's treatment into an "N of 1 study". Such studies begin with fully informed consent. When in doubt, get an opinion about this option from a colleague or a healthcare organization's risk manager.
- Neuropsychiatrists can add much value as 'treatment monitors' for CAIM treatment even when they are not directly providing them.

Rating Scales and Biomarkers (1)

- These are essential for simultaneous monitoring of multiple issues and evaluating trade-offs in treatment (e.g., Is better control of a patient's psychosis worth converting his metabolic syndrome into frank diabetes?)
- Scales can be self-rated, caregiver-rated, or collected by devices when feasible and valid. If they are clinician-rated it is best to use scales that can be validly completed by a non-physician, to reduce cost and physician time and make more frequent measurement feasible.
- Discrepancies between self, caregiver, and clinician ratings of the same items can give insight into metacognition, denial of deficits, or issues of stigma or culture-related concepts of illness.
- Know and use broadly applicable psychiatric scales like the NPI, PHQ-9, BAI, BDI, the AUDIT and the Columbia Suicide Severity Rating Scale (C-SSRI), but if you work with a specific neurological population, see if there is a special version of a standard scale that works better with your usual population.

Rating Scales and Biomarkers (2)

- Know broadly applicable functional scales like those for ADLs and IADLs, the MoCA and the clock-drawing test for cognition, and the EXIT and Trail-Making B for executive function.
- Know standard scales for pain, sleep, and fatigue – the Brief Pain Interview, the Pittsburgh Sleep Quality Index, the Epworth Sleepiness Scale and the Fatigue Severity Scale.
- Know the scales pertinent to the specific neuropsychiatric populations you treat, e.g., the UPDRS and the QUIP for Parkinson's disease, Y-GTSS for Tourette syndrome, and Y-BOCS for OCD.
- Know how to rate apathy (e.g., with the Apathy Evaluation Scale) and pseudobulbar affect (PBA, e.g., with the Center for Neurologic Study – Lability Scale (CNS-LS)) – and to distinguish them from depression.
- Know relevant state-dependent biomarkers if they exist for the neuropsychiatric disorder that you are treating
- Know scales and biomarkers for common medical comorbidities in your usual patient population.

Remember the Meaning of Life

- Meaning of life has two dimensions – long-term life goals (e.g., rearing children, practicing medicine, building a family business, living a devoutly religious life) and everyday pleasant and/or meaningful events (e.g., enjoying food, music, the outdoors, physical affection).
- Neuropsychiatric treatment often can help patients discover or better understand their meaning of life and/or enable them to pursue it more successfully.
- If a patient has a strong reason to live (= meaning of life) he/she may find new ways to solve problems and may better tolerate or adapt to what cannot be fixed.
- Neurologic treatment sometimes can be focused on enabling the patient to do what they find most meaningful. An exemplary personal case was a woman with Parkinson's disease and essential tremor who had been a successful pop singer. Adjusting her medications to give her two hours a day when she could sing easily and clearly greatly helped her depression, even though she might have off/on symptoms at other times of day or deal with a trembling soup spoon.

My Latest Breakthrough: Therapeutic Companionship - (1)



- Two years ago, I began working with a 78-year-old retired successful single woman architect who had patient who lived alone in a beautiful house. She developed agitation, loss of executive function, and severe impairment in IADLs following a right parietal lobe stroke. She had Type 2 diabetes, mild heart failure, and hyperlipidemia. She denied her illness, did not trust doctors, and wanted to continue driving her sports car.
- Her HbA1c was >12%, as she rejected treatment of her diabetes, and any other condition.
- The solution was to engage a graduating premed student with an interest in neuropsychiatry who wanted to do a gap year, experience clinical neurology, and start paying off college debt. He was hired with the aid of the patient's nephew to live with the patient at her home and provide therapeutic companionship under my supervision. He was compensated with free rent and all living expenses, plus health insurance and \$1500 per week. He accompanied the patient everywhere, drove her car, helped her with shopping and housekeeping, accompanied her to restaurants and social events, and helped her host friends. They watched movies together and played simple four-hands piano pieces. He helped care for her dog. He accompanied her to physician visits, repeatedly explained the patients diagnoses and treatments to her, and nudged her to take her meds, eat healthy, get exercise, and avoid alcohol.

My Latest Breakthrough: Therapeutic Companionship - (2)



- With his help, the patient gradually began to acknowledge her illnesses. She took oral antidiabetic medication regularly, and her HbA1c eventually came down to 7.5%. She took a short daily walk with him. She learned about mocktails – He would make them for her at home, and she would order them when they dined out.
- She learned and practiced the names of her diagnoses and the names of her medications, so she would “get more respect from doctors”. She got into learning and it became playful. For her cholesterol reduction, she would take meds that made it “easy to be me” (ezetimibe).
- Having him to drive her around town, she willingly surrendered her driver’s license.
- They would walk together from her home to local restaurants for dinner. She would introduce the young man as her houseguest.
- There would be a three-way joint video visit with me once a month, and PRN phone calls with the companion and me in between.
- A year later, the companion was admitted to a first-rank medical school (I wrote one of his recommendations). He helped recruit a successor companion, who was equally successful in supporting the patient’s care. The patient’s HbA1c reached 6%.
- The annual cost of the companion was far less than a private room in a Massachusetts SNF (\$14,000 per month). A typical hospital stay in Massachusetts costs about \$15,000, and even more if the patient remains in hospital while awaiting long-term care placement.
- At present, the therapeutic companion model is already replicable for many patients.

The Role of ‘Collaborative Care’

- ‘Collaborative care’ seems like a good idea for addressing needs for psychiatric care when there is a shortage of psychiatrists.
- However, it may work better for straightforward situations like ‘depression in primary care’ than for complex neuropsychiatric cases.
- Identifying truly complex cases (as opposed to those with a common medical condition+ common mental disorder – e.g., hypertension and mild major depression) is an important first step.
- Ultimately all care is collaborative. Even the simplest case involves more than one player – e.g., a pharmacist can potentially support – or undermine – medication adherence.

Practice the Method on Hypothetical or Historical Cases

- Case 2 – Amnestic MCI, apathy, heart failure, falls, issue of getting lost.
- Case 3 – Strokes, Bipolar II Disorder, atrial fibrillation, IDDM, COPD, legal and financial risks, driving issue.
- What is the most complex case you've seen in the past year?
 - Is the patient's current care sustainable? Is it holistic? Is it the best care you can imagine for the patient?
 - Would today's framework be applicable to the case? Why or why not?
 - Is there anything you'd do differently to make the patient's care more holistic and sustainable?
 - Are there issues in your hospital, clinic, or system that would need to be addressed to make this model of care realistic?

Can This Approach Work in Your World?

- Do you work with patients and families from a minority population or an unconventional or distinctive occupation-related subculture? Or work in a setting with limited or unusual resources?
- Is the viewpoint of this presentation compatible with that population and/or setting? Would it require adaptation?
- Is your patient volume and clinic/hospital pressure for ‘productivity’ so high that this approach seems like “pie in the sky”?
- I invite you to share your perspectives with me: bfogel@bwh.harvard.edu.