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Minimally disruptive medicine – Progress 10 years later

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Abstract

One of the greatest challenges of the 21st Century is the rising prevalence of chronic illness and multimorbidity. To meet this challenge, treatments and self-management strategies have proliferated, which health care has often delegated to patients and their families to enact. This delegation, however, has led to often unsustainable levels of treatment burden, with adverse effects on patients' lives and wellbeing. In 2009, a clinical strategy named minimally disruptive medicine (MDM) was proposed to address treatment burden, particularly in the care of patients living with multiple conditions. This proposal opened a decade of research and clinical work to better address the needs of patients living with chronic illness. In this report we describe the advances in the science and clinical care that have occurred in the decade since MDM's inception.

Abbreviations

MDM – Minimally Disruptive Medicine

PAM – Patient Activation Measure

PRM – Patient Reported Measures

Introduction

One of the greatest healthcare challenges of the 21st Century is the rising prevalence of chronic illness and of multimorbidity, the presence of two or more chronic health conditions.[1] Health care has responded with a rapid expansion of lifestyle and pharmacological recommendations, often formulated within single-disease guidelines and implemented across single-disease services. Patients and families are expected to navigate vast and complex care systems while integrating and enacting self-management regimes in daily life that healthcare delegates to them in part to accommodate the growing demands on resources posed by this tsunami of chronic illness. Furthermore, patients are expected to be active and effective participants in healthcare to achieve outcomes that others have valued as important, regardless of their value to the patient.

In 2009, May, Montori, and Mair published an article in the *BMJ* titled "We need minimally disruptive medicine."[2] In this article, they strengthened the term "treatment burden" by using it to describe the accumulation of treatment tasks for chronic conditions and the adverse consequences on wellbeing of the work patients and their supporters are expected to do to understand, access, navigate, and enact healthcare, when this work is not meaningful or adequately supported. While treatment burden had been sporadically mentioned in the literature prior to 2009 as hassles in self-management or side effects of treatments,[3-5] there was no comprehensive understanding of treatment burden or methods to systematically evaluate it across conditions. Furthermore, they proposed a new patient-centered clinical method – minimally disruptive medicine (MDM) – that called for care designed to advance patient priorities while minimizing the burden of treatment. In the decade since its publication, a substantial body of

scholarship has emerged on MDM; it was selected as one of the BMJ's most outstanding publications of novel ideas in the last two decades.[6]

The notions underlying MDM built on the germinal work of Parsons on the 'sick role' in the 1940s and of Corbin and Strauss on the "work" of managing chronic illness and identity in the mid-1980s.[7, 8] MDM recognized that not all the illness work and disease burden were obligatory features of living with a condition, but that a substantial burden is modifiable and results from how health care is organized and delivered. It put forth the claim that "non-compliance" was not an illustration of inadequate prioritization by patients, but rather a symptom that the way in which healthcare services are configured, e.g., poor care coordination, high and hidden costs, has managed to overwhelm them.[2] This article seeks to summarize the progress to date to advance the practice of MDM and to note research gaps to be addressed in the coming decade.

Conceptual and theoretical progress

While MDM provided an overall framework that moved thinking beyond the burden of symptoms and illness to consider treatment burden, additional conceptual models and middle-range theories have been developed to add depth to key concepts, particularly in relation to the workload-capacity imbalance and its consequences for clinical practice. These conceptual advances are therefore better able to indicate potential clinical actions in alignment with MDM. **Table 1** and **Figure 1** describe one conceptual framework[9] and three theories[10-12] proposed to support MDM in practice as well as suggestions of clinical actions that are in alignment with an MDM practice.

Table 1: MDM Concepts Derived from Conceptual Frameworks and Theory

MDM Concept / Middle-Range Theory or conceptual framework	Core Concepts	Examples in practice
Workload / Normalization Process Theory[12-14]	Treatment work, in order to be successful, must be normalized into patients' lives. This must occur in concert with life work that patients pursue (employment, caregiving, hobbies, etc.) Requirements to normalize treatment work: • Coherence – treatment work must make sense to patients and families. They must understand why it is important to them in the context of their life situation, and that this work has a unique contribution to living well. • Cognitive participation – treatment work must be planned, and others may need to be enrolled for assistance or support in carrying out the work. • Collective action – patients and their support network must work together in concert to ensure the treatment work, such as attending appointments and taking medications, occurs. • Reflexive monitoring – patients and those assisting must evaluate what is working and what is not working, as well as whether the work is worth the outcomes it is producing.	• In consultations, ask patients what they understand about the treatment and how they might implement it in their lives. Direct patients to key information resources. • Suggest and support methods that make treatment implementation easier. Examples include pill boxes, app reminders, or habit stacking (e.g., pairing medication taking with brushing teeth brushing). • Check in at follow-ups about how treatment implementation is going. • At review appointments revisit patient goals and priorities and adjust treatments as appropriate in consultation with patient
Capacity / Theory of Patient Capacity[10]	Patient capacity is more than just the resources that patients have to enact treatment work. Patient capacity is comprised of 5 elements: • Biography – chronic illness interrupts patients' biographies, and in doing so, takes navigating new meaning, purpose, and social roles in life. If patients are stuck navigating these transitions, they have less capacity to enact treatment work.	• Use questions such as these for clinical conversations that cover each domain of capacity: B: How are you coping with your condition? R: What would help you have success in managing your condition? E: How can I as your clinician best support you? W: What was one aspect of your treatment plan that was successful since the last time I saw you?

	• Resources – patients' ability to mobilize material and personal resources (e.g., education, self-efficacy, cognitive abilities) contribute to additional capacity for patients. The existence of resources without the ability to mobilize them does not portend capacity.	S: Who, if anyone, supports you in taking care of your health? • To the extent that is currently feasible, measure patient capacity. For example, a brief 6-item assessment of self-efficacy to manage chronic disease may be insightful.[15]
	• Environment – patients' environments, including home and community, work, and healthcare, contribute to capacity. If the healthcare environment places significant barriers to patients, such as disbelief in symptoms, complex structures in accessing care, or one-size-fits-all treatment approaches to care, this will be detrimental to patient capacity.	
	• Work – The successful experience of enacting treatment work can perpetuate the feeling of success and lead to greater capacity to enact additional treatment work.	
	• Social – Patients' social networks can be supportive of capacity to enact work or can be detrimental to that pursuit.	
Workload-Capacity Imbalance/ Cumulative Complexity Model[9]	• Workload-Capacity imbalance leads to difficulty accessing and using healthcare as well as enacting self-care at home • These difficulties can lead to poor health outcomes and reduced quality of life • Current healthcare structures do not diagnose workload-capacity imbalance. Instead, worsening outcomes trigger treatment intensification. • Intensifying treatment increases treatment burden while patient capacity continues to deteriorate from increased illness burden. This results in a cycle of continued workload-capacity imbalance.	• Consider the extent to which missed appointments, non-adherence to treatments, or difficulties with self-care tasks may indicate a workload-capacity imbalance. • Measure treatment burden at regular intervals. • Consider whether worsening outcomes warrants additional treatment or other action such as more support. • Identify opportunities for treatment workload de-escalation and de-prescribing where it aligns with patient priorities.

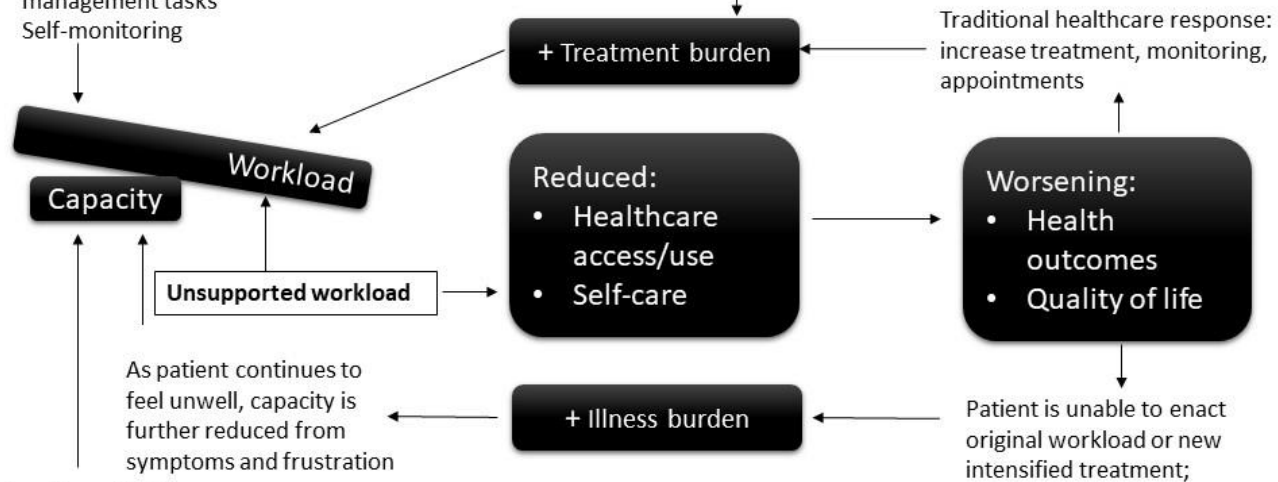| **Treatment Burden / Burden of Treatment Theory**[11] | Capacity and work are dynamic and interdependent. Appropriate interventions on capacity and workload can reduce treatment burden. These interventions include:
• Building and strengthening relational networks around sick people and better equipping them to navigate the healthcare system.
• Facilitating work to secure co-operation and social capital.
• Facilitating control and monitoring effects of tasks delegated to patients and families.
• Maximizing collective competence in enacting practical tasks, distributing help, and exploiting local resources.
• Ensuring services are accessible
• Making sure that the way services are configured, and supports are tailored to meet patient needs. | • Determine the extent to which the patient's local healthcare context contributes to workload and/or capacity.
• Explore local networks that can support patients as they access and use the healthcare system and enact self-care.
• Engage caregivers that accompany patients to appointments to understand their role in the patient's life and the extent to which they assist the patient in caring for their health. |

Workload drivers (NPT)
- Life demands
- Confusing treatment plans
- Poorly coordinated care
- Enrolling support from others
- Planning & enacting self-management tasks
- Self-monitoring

Treatment burden increases (BoTT)
- When capacity and workload are ignored in the design of healthcare services and clinical care
- When patients' relational networks are ignored

+ Treatment burden

Traditional healthcare response: increase treatment, monitoring, appointments

Workload

Capacity

Unsupported workload

Reduced:
- Healthcare access/use
- Self-care

Worsening:
- Health outcomes
- Quality of life

As patient continues to feel unwell, capacity is further reduced from symptoms and frustration

+ Illness burden

Patient is unable to enact original workload or new intensified treatment; continues to feel worse

Capacity drivers (TPC)
- Biography: a coherent sense of self, meaning, purpose, social roles
- Resources mobilized: education, self-efficacy, finances, etc.
- Environment: home, work, healthcare
- Accomplishment of patient work
- Social support

Figure 1: MDM Conceptual and Theoretical Summary

Key
NPT = Normalization Process Theory
TPC = Theory of Patient Capacity
BoTT = Burden of Treatment Theory

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Foremost, MDM is a clinical method that acknowledges patient and caregiver experiences of workload and capacity, and that informs humane responses to these. It promotes changes in clinical behavior and the restructuring of clinical services that take patient values, preferences, goals, and priorities into account and seeks to reduce the (iatrogenic) burdens that the healthcare system produces. MDM calls for the development of individualized interventions that support patients as they face new forms of work and seek to enhance their capacity to act upon them, taking into account the challenges and opportunities posed by a patient's individual context at any given time. It also calls for ways to rethink and restructure clinical work and clinical workplaces so that they better meet patient needs and emphasizes the need for greater care coordination and the importance of the generalist role in clinical medicine.

What have we learned about patient work and treatment burden?

The work patients must do and its associated burden has now been documented in a variety of clinical conditions.[13, 14, 16-18] In the process, we have learned about some contributors to treatment burden including (a) the nature and meaning of the tasks imposed on patients and their families, such as medication management and lifestyle changes; (b) structural challenges, such as access to healthcare resources and poor coordination between care providers; (c) personal, situational, and financial factors that further frustrate the completion of tasks or impair access to facilitating resources; and (d) consequences of the burden such as poor adherence to treatments and the impact on finances as well as professional, family, and social life.[19-21] We also have some evidence regarding the prevalence of self-reported levels of unsustainable treatment burden (~40% of patients report this level of burden) as well as patient situations that are

correlated with increased treatment burden including living with a mental health condition, the number of chronic conditions, polypharmacy, and younger age.[22-25]

A key contribution to determine the prevalence and extent of treatment burden has been the development of patient-reported measures (PRM). While condition- or treatment-specific treatment burden PRMs previously existed,[26] the rise in multimorbidity has challenged researchers to develop treatment burden PRMs that strike a balance between gaining an in-depth understanding of the treatment burdens imposed by individual conditions and also capturing the broader, cumulative burdens imposed by multimorbidity. Three non-condition-specific treatment burden patient-reported measures (PRMs) now exist: 1) the Treatment Burden Questionnaire (TBQ);[27] 2) the Patient Experience with Treatment and Self-management (PETS) questionnaire;[28] and 3) Multimorbidity Treatment Burden Questionnaire (MTBQ).[29]

All three PRMs have been validated in a variety of conditions and research is ongoing to test and validate them further in a wider range of patient groups. As well as the standard considerations of construct validity and reliability, important characteristics when considering using these scales clinically include face validity in a relevant patient group, length (as this affects usability for both patient and clinician), language, indicative cutoffs for clinical action, and responsiveness to change. These characteristics are provided in **Table 2.**

Table 2: Validated Measures of Treatment Burden				
Measure	Length	Available Languages	Cutoffs for Clinical Action	Responsiveness to Change
Treatment Burden Questionnaire (TBQ);[27]	15-items	English,[30] French,[27] or Spanish.[31]	Score of 59 out of 150 indicates patient treatment burden is likely unsustainable over time.[24]	Not explored but has detected changes in treatment burden after chronic illness intervention in at least one non-randomized trial.[32]
Patient Experience with Treatment and Self-management (PETS) questionnaire;[28]	60-item version[28] or 34-item version,[33] both divided into sub-scales	English[28, 33]	Not yet established	Demonstrated; increased treatment burden scores over time are correlated with simultaneous declines in patient self-efficacy, global mental health, and global physical health.[22]
Multimorbidity Treatment Burden Questionnaire (MTBQ).[29]	10-items[29] with 3 optional items related to cost of care and access to services for US context	English[29] and Chinese[34]	Not yet established	Not yet established

What have we learned about patient capacity?

Compared to the significant advancement of our understandings of and ability to measure patient work and treatment burden, advancement of the science regarding patient capacity has experienced slower progress in the past decade and deserves significant attention in the coming one. In part, this deficit may be due to the relative clarity that treatment burden was a previously unidentified concept clearly at play in patients' ability to adhere to treatments. On the other hand, patient capacity was originally described as patients "abilities and resources" to access and use care and enact self-care. Abilities and resources seem relatively clear cut. Yet the research on the topic now illustrates that the concept of patient capacity is more complex and dynamic than expected and is poorly captured in clinical care.[10, 35, 36]

If we consider patient capacity to include the constructs described in the Theory of Patient Capacity (Table 1), no single comprehensive measure of patient capacity exists, and related measures are currently insufficient to capture the concept. For example, the most often suggested is the Patient Activation Measure (PAM), a proprietary measure of the extent to which patients are "activated," engaged, or ready to be engaged in their care.[37, 38] However, capacity precedes patients' abilities to be activated in their care. If a patient has limited capacity, there may be suboptimal or no activation or engagement as defined by PAM. Evidence of this relationship exists in research illustrating that amongst complex patients; PAM scores and concepts related to capacity such as depression, lower health literacy, health-related quality of life, number of comorbidities, perceived impact of multimorbidity, social support, education, and financial strain are correlated.[39 40] Unpacking these differences in capacity and activation

becomes more relevant as organizations seek ways of measuring these concepts. For example, the PAM is currently utilized as a quality metric in new payment models such as the Centers for Medicare and Medicaid Service's Kidney Care Choices Model, an optional payment model for organizations treating patients with end stage kidney disease.[41]

More recently, a general measure of "flourishing" has been suggested for use in clinical care.[42] This measure draws its origins from positive psychology and is based on six domains: happiness and life satisfaction, physical and mental health, meaning and purpose, character and virtue, close social relationships, and financial and material stability.[43] These closely align with capacity concepts described by both Boehmer et al. and Gallacher et al.[10, 36] However, it is important to note that this measure was proposed from an unsystematic search of the literature,[44] was validated in a population of healthy individuals rather than those living with chronic illness,[43] and did not include patient or other stakeholder involvement in its development.[44] Ultimately, either measure is insufficient to drive changes in clinical care to support patients' capacity, as we still cannot determine unsustainable levels of reduced capacity, nor which domains require bolstering to best support a patients' overall health and quality of life.

Interventions to enact minimally disruptive medicine in clinical practice

Two interventions have been developed explicitly in alignment with MDM: the ICAN Discussion Aid and Capacity Coaching.[45, 46] Additionally, while MDM has not been implemented in a full-scale clinical intervention, it is worth discussing practical interventions with a similar objective: improving outcomes for patients with multimorbidity.

The ICAN Discussion Aid was developed with a user-centered design approach to foster conversations about treatment burden and patient capacity in patient-clinician encounters.[46] It is

flexible rather than prescriptive in its approach to use and leaves the problem solving around issues that come up to patients and clinicians to consider together.[46] In its pilot evaluation, primary care clinical encounters had significantly different conversations, specifically introducing more conversation about issues of dietary and physical activity recommendations, medication taking, and competing priorities.[47] Overall, the aid was perceived as feasible for use in primary care and did not add time to visits, with an average visit time of 31.6 minutes with ICAN versus 34.5 without the aid.[47] Appointment times in the pilot context were longer than many other settings, and this is a recognized limitation. A pragmatic trial of ICAN has been completed in the US and results will be available soon.

Capacity Coaching is an intervention, expanding on the ICAN Discussion Aid work, designed to reduce patient workload and increase patient capacity.[45] Capacity Coaching was designed using the underpinning principles and practices of traditional Health and Wellness Coaching, such as establishment of a strong coach-patient relationship, establishing a vision for health and wellness, and goal-setting.[45] However, Capacity Coaching layers on coaching actions that are in alignment with the Cumulative Complexity Model and the Theory of Patient Capacity to better address the needs of patients living with multimorbidity.[45] For example, patients may be overwhelmed by their current set of healthcare-related tasks, and the Capacity Coach would work with the patient and their healthcare team to potentially reduce some of that work temporarily or permanently.[45] Additionally, Capacity Coaching pays greater attention to overcoming "biographical disruption,"[48] a period following the diagnosis of a chronic condition in which the patient's sense of purpose and meaning and social roles are upended.[45] In a qualitative evaluation of the program's pilot, it was determined to be feasible and positively received by staff and patients alike.[49] However, sustained implementation would require a

comprehensive evaluation of the program's impact on patient outcomes, patient and healthcare system costs, and workforce availability, as well as greater engagement of top-level leadership.[49] Quantitative evaluation of the intervention's effects on treatment burden, health outcomes, and quality of life is still needed. Long follow-up periods should be considered in the evaluation given how multimorbidity affects patients' lives over long periods of time.

As well as aiding the design of new interventions, MDM as a framework can guide our understanding of where current literature about multimorbidity interventions makes a contribution and where gaps remain. The most recent Cochrane review of the effectiveness of interventions for patients with multiple chronic conditions grouped these interventions into patient-focused (self-management support) or organizational-focused (altering care delivery structures). This review found small effects of both types, slightly in favor of organizational-focused interventions.[50] More recent randomized controlled trials evaluating a mixture of patient-focused and organizational-focused interventions for multimorbidity similarly have mixed results and expand minimally on that covered in the previous review.[51-53] Non-randomized interventional studies without control groups that have followed patients for under 2 years have demonstrated improvements in contributors to patient capacity – e.g., patient wellbeing, physical activity, mental health, and loneliness – through social prescribing programs that connect patients with non-medical sources of support.[54] Additional multimorbidity programs that are currently being implemented at large include Australia's Health Care Homes program[55] and the UK's "House of Care" model.[55-57]

Many of these studies used the Chronic Care Model to design their interventions, which has been noted to need revision given the challenges of multimorbidity.[58, 59] Given the ongoing and long-term nature of multimorbidity, studies have ascertained outcomes in too short a time

frame. We hypothesize that using MDM to design interventions and the trials to evaluate them may advance the care of patients with multiple chronic conditions. For example, rather than interventions focused solely on diminishing patient workload (by changing healthcare delivery structures) or on increasing patient capacity (through self-management support or social prescribing), MDM suggests that interventions should attend to the balance of workload and capacity.

MDM would also suggest greater participation of patients in intervention development than is evident in studies included in the Cochrane review.[50] In addition to broad systematic reviews of the patient experience of living with complex chronic conditions,[10, 13, 14, 17, 60] on how patients would improve care for patients living with chronic illness[61] and reduce their treatment burden.[62] Specifically, patients emphasize the need for tailored information, helpful patient-clinician conversations (humanistic, non-stigmatizing, and trusting of patients' lived experience), personalized care goals, and adaptations of treatment and home care to fit each patient's situation.[61] Beyond encounter-level suggestions, patients also recommend system level changes, such as more patient-centered scheduling, connection with other patients for peer support, and reduced fragmentation of care.[62]

Discussion

To illustrate some of these advances, we introduce you to a hypothetical patient scenario where the clinical team acts in accordance with MDM practices in **Box 1**. This illustrates how workload and capacity issues interact to produce treatment burden, affecting patient outcomes. It also shows how individual practitioners and health care systems can act to influence both factors in ways that are likely to enable and enhance patient outcomes. An important frontier in this work

is the ways in which healthcare systems can be organized to effectively support the provision of care that is flexible and responsive to the fluctuations in each patient's workload, capacity, and resulting treatment burden over time.[63] This requires high level buy-in and investment. Comprehensive interventions based on MDM hold the promise of improvements in the care of people living with multiple chronic conditions that have remained elusive to date.

While there are emerging examples of MDM being rolled out at scale in clinical practice, the challenge is to make MDM approaches to healthcare delivery ubiquitous. The current COVID-19 pandemic is producing rapid change in approaches to health care delivery with digital health services rapidly becoming mainstream. This reconfiguration of healthcare provision poses risks but also provides opportunities to integrate MDM approaches as part of these changes. Now more than ever, we need to utilize measures of treatment burden and develop measures of capacity to enable us to identify those most at risk from new digital approaches to healthcare delivery and to ensure that the current transformations in healthcare are beneficial to the growing population of patients with complex multimorbidity. We also should consider workload that results from the pursuit of vaccination and the impact of capacity on vaccination status. Successful vaccination programs of patients with multimorbidity must consider the limited available capacity of the participants. Thus, for example, vaccination sites (e.g. work sites, community centers) and times (e.g. before or after working hours, adjacent to already scheduled appointments) that require little to no rework of a person's routines may be more successful than those that are necessarily disruptive of these routines. MDM requires re-imagining of healthcare delivery with patient goals and priorities at the center and greater emphasis on generalist approaches and improving care coordination. Incentivization of such approaches rather than fee for service reimbursement would likely accelerate change.[64-66] With

the growing complexity of our patient populations, the status quo is unsustainable. Fragmented, poorly coordinated care that does not put patient goals and perspectives front and center is unlikely to achieve positive care outcomes for our patients with multiple health and social problems. Understanding patient priorities, their workload and issues that will influence their capacity to engage effectively with self-management is key to successful healthcare delivery.

Box 1. Minimally disruptive medicine in action – Bob's Story

The Patient Situation

This patient, who prefers to go by Bob, is 61 and works full time as an accountant at a large corporation (workload). He is married and has two grown children and finds his family to be a source of joy for him (positive impact on capacity, "Social"). He lives with obesity, sleep apnea, chronic pain with exertion on his lower back and hips, hypertension, and type 2 diabetes (negative impact on capacity, "resources"). He monitors his blood pressure and blood sugars closely and writes the numbers down on a spreadsheet (workload). He wears a smartwatch that tells him how many hours of deep sleep he has per night which also go on the spreadsheet (workload). He takes two tablets twice a day for diabetes in the morning and a cholesterol-lowering tablet and an antihypertensive tablet in the evening (workload). He complains that his antihypertensive gives him a cough and this impacts his energy greatly (treatment burden). Despite all his efforts, Bob's control of his hypertension and diabetes is, according to his doctor, "poor" (negative impact on capacity, "Environment").

He has an old CPAP machine, but he does not use it because it is noisy, preventing he and his wife from falling asleep (treatment burden). He does not remember it ever helping. For meals, he has coffee for breakfast, fast food meal for lunch, and whatever his wife cooks for the evening meal, which is often meat and potatoes along with one or two beers (capacity, "social"). He has found no success in changing his eating patterns because he is frustrated every time something at work comes up and derails him (negative impact on capacity, "work"). He considered adding an expensive medication capable of controlling diabetes while promoting weight loss and lower blood pressure, but Bob decided to postpone its use because of financial considerations (capacity, "resources"). Bob's boss has expressed concerns about the accuracy of his work and alerted Bob that his colleagues are commenting about his tendency to easily fall asleep in team meetings and in his office. In their last meeting, he asked Bob about his plans for retirement, which was deeply troubling since Bob has long found meaning in his work (capacity, "biography").

Minimally disruptive care

Working with Bob, his clinical team determined that his treatment burden is unsustainable (using the TBQ Bob completed before the visit) and that he needs self-management support to boost his capacity (using the ICAN Discussion Aid with Bob during the visit) and to achieve his goals (clarified through discussion). Bob's doctor arranged for Bob to get a quieter and better fitted CPAP machine. His doctor's assistant helped Bob complete and file the insurance paperwork to cover the cost. The nurse trained Bob's wife in supporting his use of the CPAP

machine. This nurse, trained in Capacity Coaching, worked with Bob and his wife for 3 months on adopting helpful self-management strategies. This nurse also helped to address frustrating and conflicting dietary advice and to adopt modifications to his food and alcohol intake to better manage his hypertension, diabetes, and weight. Bob's clinician had explained that physical activity could improve his chronic pain, induce weight loss, and control his hypertension and diabetes without the need for more medications. Yet, moving hurt. After a brief in-person physical therapy session, Bob attended subsequent sessions online, receiving just-in-time feedback about his efforts. Concerned with the burden of treatment, Bob's clinician had asked him to stop daily glucose self-monitoring (they would rely instead on a periodic HbA1c test). However, a sense of control was important to Bob. Realizing this, the Capacity Coach helped Bob reorient his glucose self-monitoring toward evaluating his dietary changes, which Bob, a tinkerer by nature, found interesting and motivating.

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