



ORIGINAL ARTICLE

Pursuing minimally disruptive medicine: disruption from illness and health care-related demands is correlated with patient capacity

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Abstract

Background: Chronic conditions burden patients with illness and treatments. We know little about the disruption of life by the work of dialysis in relation to the resources patients can mobilize, that is, their capacity, to deal with such demands. We sought to determine the disruption of life by dialysis and its relation to patient capacity to cope.

Methods: We administered a survey to 137 patients on dialysis at an academic medical center. We captured disruption from illness and treatment, and physical, mental, personal, social, financial, and environmental aspects of patient capacity using validated scales. Covariates included number of prescriptions, hours spent on health care, existence of dependents, age, sex, and income level.

Results: On average, patients reported levels of capacity and disruption comparable to published levels. In multivariate regression models, limited physical, financial, and mental capacity were significantly associated with greater disruption. Patients in the top quartile of disruption had lower-than-expected physical, financial, and mental capacity.

Conclusions: Our sample generally had capacity comparable to other populations and may be able to meet the demands imposed by treatment. Those with reduced physical, financial, and mental capacity reported higher disruption and represent a vulnerable group that may benefit from innovations in minimally disruptive medicine. © 2016 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Keywords: Minimally disruptive medicine; Chronic care; Patient-centered care; End-stage renal disease; Dialysis

1. Introduction

Chronic conditions, defined as lasting 12 months or more and limiting self-care, independent living or require ongoing medical intervention [1], require ongoing, typically lifelong treatment that is burdensome to patients. Estimates in 2013 indicated that 117 million, or approximately half of adults in the United States, had one or more chronic conditions [2], whereas 26% of adults in the United States had multiple chronic conditions, up from 21.8% in 2001 [3]. Certain populations of patients with chronic conditions have a higher prevalence of comorbidities, such as patients with chronic kidney disease, where the prevalence of comorbidities has been estimated at 56–86%, increasing with the severity of the disease [4,5].

Chronic conditions cause pain, fatigue, and other symptoms, as well as functional limitations, which contribute to the burden of illness. Additionally, they place another burden on patients, this one arising from treatment tasks [6]. Treatment burden can be defined as treatment work, delegated by health care systems to patients and its impact on their functioning and well-being; there are growing demands on patients to organize their own care and self-manage to comply with complex regimens [7,8]. A recent systematic review found that patients with chronic conditions spent on average 86 minutes per day managing a single condition and 35 additional minutes for recommended exercise. Although not daily, patients report spending 104–151 minutes for each health care encounter, including transportation, waiting, and receiving care [9]. Further complicating chronic care is the disease-centered nature of clinical practice guidelines and quality metrics. Guidelines often fail to consider comorbidities, treatment burden, patient preferences, or patient context [10]; the consequence of their additive, uncoordinated, and often contradictory tasks is increased treatment burden [11].

Conflict of interest: None.

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What is new?

- The Cumulative Complexity Model was published in 2012 as a conceptual model to guide research, innovation, and implementation of minimally disruptive medicine (MDM). This is the first article that seeks to provide prospective exploration of model concepts. Specifically, this article explores a population with a high workload, providing the ability to explore domains of patient capacity to enact that work. Additionally, because this patient population must adhere to treatment for survival, disruption presumably affects their ability to pursue their life's joys, which we have measured through illness and treatment intrusiveness.
- Patients on dialysis report capacity and disruption from illness and treatment that is comparable to other populations on average. However, patients most disrupted by their illness and treatment had deficits in their physical, emotional, and financial capacity.
- Chronic conditions and the burden of their treatment can overwhelm patients' lives. Clinical care should seek to identify patients that may be overwhelmed by their care and identify and address capacity issues that patients may have. Where capacity issues cannot be addressed by the health care system, treatment plans should be adapted. This requires careful clinical conversations about coping with treatment and patient capacity, of which innovations in MDM can support.

Treatment burden alone is not the only factor: Eton et al. found that multiple contextual issues may exacerbate treatment burden, such as challenges taking medications, emotional problems with family and friends, role and activity limitations, financial challenges to afford and access health care, and health care delivery inefficiencies [12]. All of these can be considered barriers to patients accessing their available abilities and resources to meet treatment needs.

Minimally disruptive medicine (MDM) accounts for these factors and is an approach to care emphasizing the "fit" of health care to patients' lives [8,13]. It is grounded in the Cumulative Complexity Model (CuCoM, see Fig. 1), a model of patient complexity that outlines how clinical and social factors complicate care and outcomes [14]. In the CuCoM, every patient has a set of demands and responsibilities in his or her life, which constitute the patient's "workload." This workload includes a person's health care tasks, but also competing demands required for other life roles as parents, spouses, friends, caregivers, workers, and

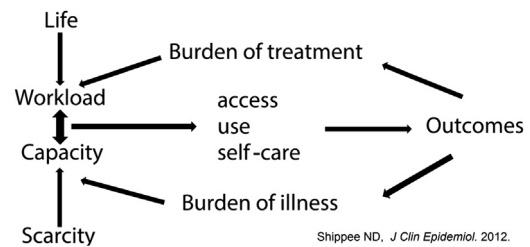


Fig. 1. Cumulative Complexity Model.

community members. In meeting these demands, patients have a finite capacity, which can be described as the abilities and resources they can mobilize to manage this workload [14]. In some ways, our theoretical understanding of capacity comports with the Conservation of Resources Theory, which states that people have objective resources, conditions, personal characteristics, and energies available; they seek to conserve these resources as they interact with their environment and loss of them may cause stress [15]. For example, to address high self-care demands, a patient may use their high health literacy to quickly and effectively make sense of complex self-care regimens and multiple follow-up visits to several physicians and solve problems; or may enroll a spouse on whom to delegate the tasks of organizing medications; or partner with a well-coordinated health care system able to support self-care.

For some patients, capacity is sufficient to meet the demands of care and the demands of life. However, others experience an imbalance—that is, when workload exceeds capacity. The CuCoM posits that this imbalance means that patients may be unable to access and use health care and perform self-care alongside the other demands in their lives [14]. Such an imbalance, we call disruption, could manifest in two ways: (1) patients prioritize life's demands, disrupting treatment adherence and self-care, and therefore resulting in worsening clinical outcome markers or (2) patients prioritize necessary clinical care and self-care at the cost of disrupted lives, manifesting as intrusion to their ability to carry out meaningful activities such as hobbies and relationships. Although some patients can afford the former with few immediate consequences, those with life-threatening conditions requiring close control (e.g., dialysis, highly active antiretroviral therapy for HIV) have little option but the latter, meaning both illness and treatment, become intrusive on their lives.

Despite some work on understanding and measuring burden of treatment [6,7,12,16–18], patient capacity remains largely unexamined. Certain domains of patient capacity have, in isolation, been shown to affect patient outcomes and behaviors [19,20]. Fatigue and self-efficacy have been shown to be associated to self-management behaviors [19–22], pain with depression status and coping ability [23], financial hardship, and social support with quality of life and mortality [24–31]. Attending to such

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