



Patient and family burden of management: we need new knowledge

Charles Leduc MD MSc FCFP
Head, Academic Department of Family Medicine
Cumming School of Medicine

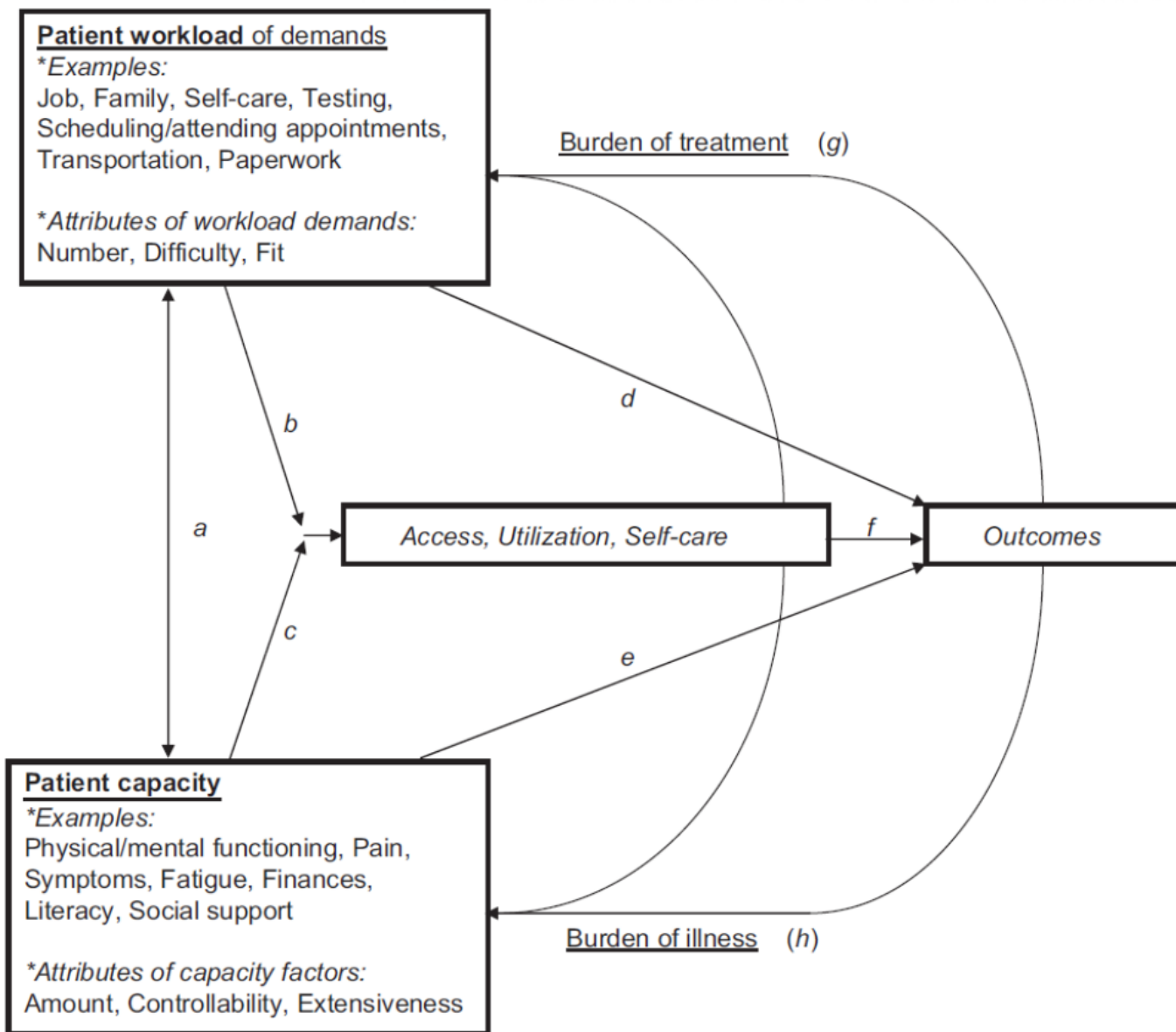
“Care that is truly patient-centred considers patients’ cultural traditions, their personal preferences and values, their family situations, and their lifestyles. ***It makes patients and their loved ones an integral part of the care team*** who collaborate with health care professionals in making clinical decisions.

Patient-centred care ***puts responsibility for important aspects of self-care and monitoring in patients’ hands*** – along with the tools and support they need to carry out that responsibility.

Patient-centred care ensures that transitions between providers, departments, and health care settings are respectful, coordinated, and efficient.”

(Institute for Healthcare Improvement, 2007. *Patient-Centered Care: General.*)

What do we know about the burden of disease management?



(Schippee, 2012)

Fig. 2. The cumulative complexity model.

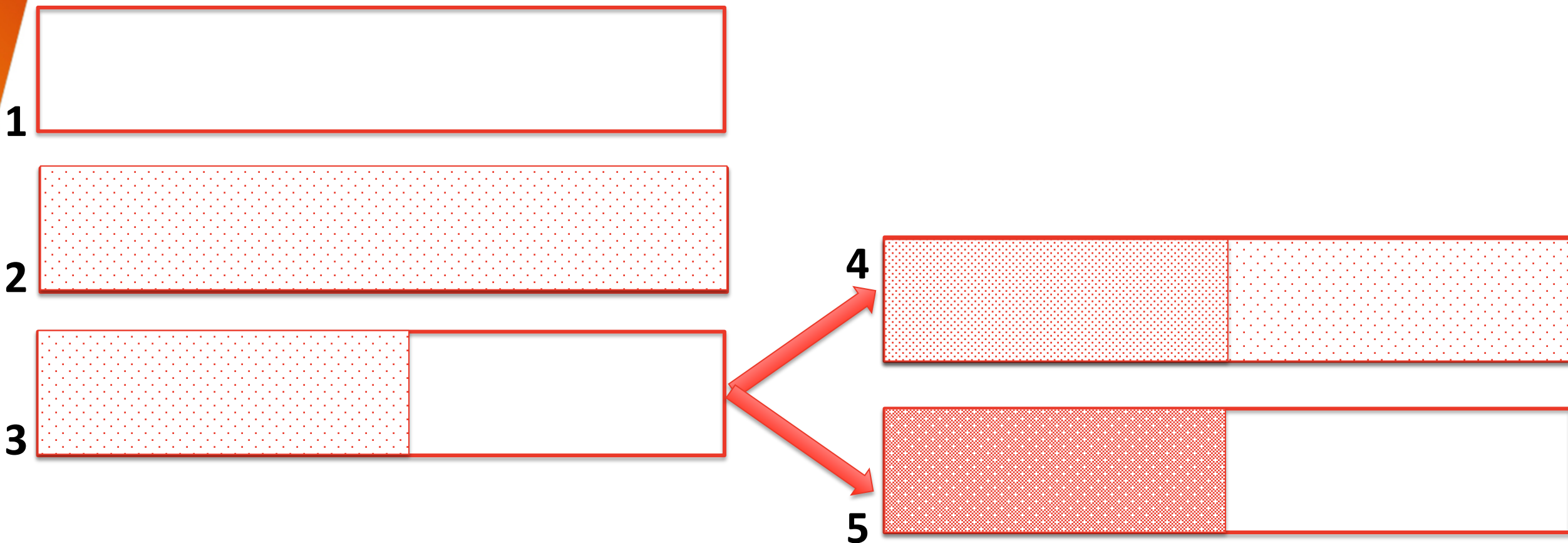
- Shared decision making appears to be an equal opportunity option
- Workload-capacity imbalances tell us otherwise

- What happens when we « shift the conversation from “What’s the matter?” to “What matters to you?”
- Patient preference may consolidate health disparities
 - American blacks’ vaccination rates are uniformly lower than whites, independently of the structure of care
 - Women perceive the risk of joint replacement surgery to be higher than men, and clearly higher than documented
 - Many patient seek care from physicians from the same ethnic background; and estimates of benefit are uniformly higher amongst white physicians than those from other ethnic background

(reported by Katz, 2001)

- “It is the patient who ultimately must make informed choices about the care he or she will receive.”
(Putting patients first®: Patient-centred collaborative care. A discussion paper. July 2007. Canadian Medical Association.)
- Sounds good...
- A background of historical oppression or social inequity will not make the statement a collaboration but may reinforce pre-existing negative determinants of health.

- Intervention to nurture resilience might increase the density of suffering rather than decrease it



- “Patients with few demands but low capacity may experience burden whereas those with many demands but high capacity may not.” (Ridgeway et al, 2014)
- ...and we know they are often not easy to differentiate.

“Happy families are all alike; every unhappy family is unhappy in its own way.”

(Leo Tolstoy, *Anna Karenina*. 1878)



- How do we integrate the good intentions of PCC and the reality of life for our patients with scarce capacity?
- Are we looking for harm?
- Can we develop the measures of increased burden at the same time as we do the measures of success?
- How are we using the unique environment and community of Alberta to assess the personal, social and economic determinants of the capacity to deal with the burden of multimorbidity management?

- Recording Reported Outcomes and Experiences will be influenced by our own values, the dominant culture, and a western scientific tradition of « wanting to do good »
- We need new knowledge about the impact of historical oppression on PROMs and PREMs
- We need new knowledge about heretofore occult cultural determinant of experience on patient-provider relationships
- We need to understand our own scientific and clinical blindness and their influence on PROMs and PREMs

1. Katz JN: *Patient preferences and health disparities*. JAMA 2001;286(12):1506-9.
2. Sav A, King MA, Whitty JA, et al: *Burden of treatment for chronic illness: a concept analysis and review of the literature*. Health Expect 2013 January:1-13
3. Barnett K, Mercer SW, Norbury M, et al: *Epidemiology of multimorbidity and implications for healthcare, research, and medical education: a cross-sectional study*. Lancet 2012;380:37-43
4. Shippee ND, Shah ND, May CR, et al: *Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice*. J Clin Epi 2012;65(10):1041-1051
5. Ridgeway JL, Eggington JS, Tiedje K, et al: *Factors that lessen the burden of treatment in complex patients with chronic conditions: a qualitative study*. Patient Preference and Adherence 2014;8:339-351
6. Rademakers J, Delnoij D, Nijman J, de Boer D. *Educational inequalities in patient-centred care: patients' preferences and experiences*. BMC Health Services Research 2012, 12:261-9
7. Pulvirenti M, McMillan J, Lawn S. *Empowerment, patient centred care and self-management*. Health Expectations 2014;17(3):303–310



...I'll take care of you I said. Noooo! No more blankets!