Patient and family burden of management: we need new knowledge

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“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)
Empowerment, delegation and duty shifting

- Shared decision making appears to be an equal opportunity option
- Workload-capacity imbalances tell us otherwise
What do we know about the potential harms of a PCC paradigm?

- 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)
PCC is not devolution of clinical responsibility

- “It is the patient who ultimately must make informed choices about the care he or she will receive.”
- 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.
The non-clinical, occult factors of possible harm

- “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)
Our duty to create new knowledge

- 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?
How does this affect PROMs and PREMs?

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