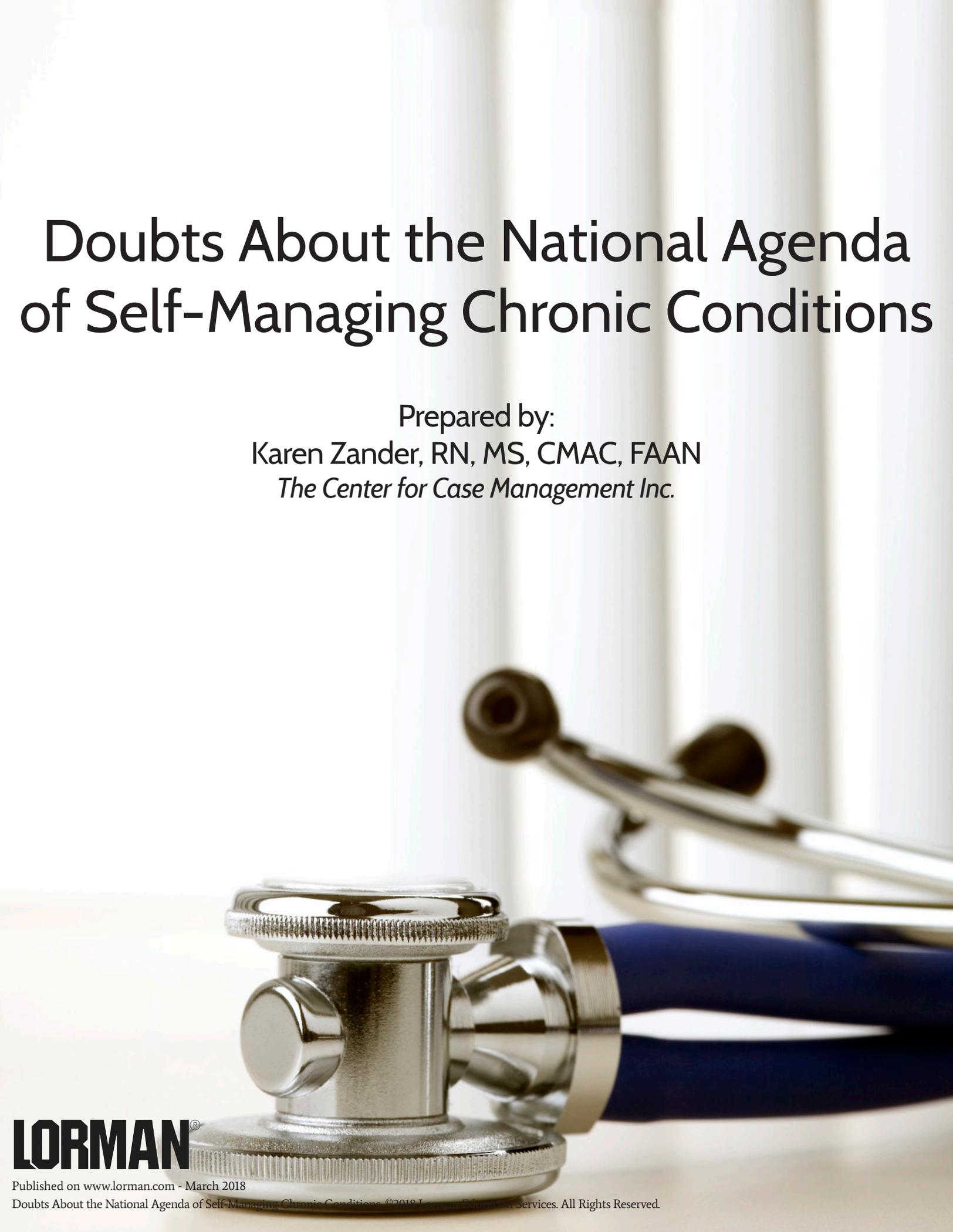


Doubts About the National Agenda of Self-Managing Chronic Conditions

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DOUBTS ABOUT THE NATIONAL AGENDA OF “SELF-MANAGING” CHRONIC CONDITIONS

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The Logic

You know you have passed over some invisible line when you begin to take pride in your ability to pour out the exact number of pills from each bottle that your “Day-Evening-Nite” pill container requires. Similar accomplishments are only the first chapter of our country’s insinuated goal that we all become empowered “self-managers” of our health, thereby putting less of a financial burden on healthcare providers and insurance companies, especially Medicare (Weinstock, M. (January 26, 2015) Burwell: Tie More Medicare Pay to Quality and Value; Hospitals and Health Networks Daily; retrieved 2/2/15.). For example, hospitals are currently being penalized reimbursement from Medicare and other payers if patients and their families do not reach a sufficient level of self-management within 30 days of discharge, thus requiring additional ED visits and possible readmissions.

Basically following through the logic to its ultimate conclusion is:

- Payers and providers will be able to sustain a profit margin if patients and their families don’t need a lot of utilization of services—especially those with chronic diseases and conditions because they can be very expensive;
- In order to keep them from needing those services, they will either require better care coordination throughout all levels of care by doctors, social workers, and RN case managers, or they will need to be able to manage their own care and coordination as much as possible;
- Therefore, the patient and their family that are able to reach a level of self-management will cost payers and providers less money than those that don’t.

Expecting that a large majority of the US population will take responsibility for their health and behavior to achieve self-management, also referred to as self-efficacy, is a huge financial and psychological gamble, and I for one have deep doubts.

Chronic illnesses and conditions are “severe and persistent” and by definition, irreversible, non-curable, and permanent without miracles or medical discoveries. There may be remissions and exacerbations, but the underlying pathology (and sometimes the lifestyle that has contributed to it) never goes away. Almost everyone I know-- of any age-- has something “chronic” going on, whether allergies, migraine headaches, sleep disturbances, arthritis, dysfunctional families, diabetes, and more severe conditions like multiple sclerosis. According to the CDC, one third of the US population has at least one chronic disease and 85% of all healthcare dollars go to treatment of chronic diseases. “Chronic conditions place the patient at significant risk of death, acute exacerbation/decompensation, or functional decline”.¹ Even though not included in that definition, aging all by itself could be considered a chronic condition!

People who reach the self-management level for their own care and the prevention of even worse maladies didn't start out that way. Rather, they have been on a journey acquiring both knowledge and also fundamental skills and values to support that knowledge. What motivates them, after everything is said and done, is their ultimate fear of an earlier death than they had expected. Even the most self-disciplined, motivated, health-seeking person can be greatly discouraged by the relentless attacks of their chronic disease(s).

The Reality

In my experience as a T4-6 paraplegic for the last 7 years, fear is truly the biggest motivator to do the right (healthy) things for myself. For example, fear of a fractured hip from the osteoporosis that my spinal cord injury created leads me to force myself to take a daily injection required for two years, even though I was extremely angry that I had to self-manage yet one more (very expensive) thing. Plus the particular drug has been shown to produce osteosarcoma in rats, so my choice was a “lose-lose” choice between possible cancer of the bone vs. a fractured hip. And so it goes for many of us, having to choose between the better of two evils. Being a self-manager can be exhausting, not to mention what it is like for friends and family. One of my colleagues accurately characterized chronicity as a “home invasion”. My friends and family are willing to learn about my condition, try to be supportive, and usually stay vigilant in case my self-managing self becomes weary of the battle.

The journey toward efficacy begins with shock and disbelief about the diagnosis and condition, progresses to a level of strict compliance with medical advice, than moves to adherence in which we can make adjustments for unusual situations, and only finally reaches the a level of self-management (Hamilton, Glenys A. et al; Health Values: The Journal of Health Behavior, Education & Promotion, Vol.17(1), Jan-Feb 1993, 3-11) I have noticed that significantly accelerating the journey requires three things on the patient's side:

- 1) At least one someone (if not a whole family) who loves you--even when you don't love yourself much and are being obnoxious,
- 2) A network of professionals tracking and coordinating your condition and healthcare

¹ CMS Final Rule; CPT (Current Procedural Terminology) Professional Codebook; American Medical Assn.

3) Antidepressants if needed

Although a cliché, self-managing people take each day as it comes, trying not to get overwhelmed by the life sentence of chronicity. Otherwise, we wouldn't ever want to get out of bed! Like surfers on waves, we are dependent on the good wishes and professional skills of others. They help us love ourselves a little more on those days when we don't love ourselves very much.

We self-managing people have a lot on our minds, including ordering equipment and medications, as well as many appointments to both make and keep. We generally don't want to be seen as "patients", or heroes, or resilient. This is NOT the "new normal" because we can still remember what real normal was. Instead, we want to be connected and accepted despite our specific chronic ailment(s). I have observed that we are often busy managing other people's reactions and expectations. In fact, we may sometimes lie about ourselves and how we are feeling physically and/or emotionally in order to control what we see as the bigger picture—such as an evening out with good friends or a special event, or maintaining a positive relationship with our physicians. At times, pride and self-esteem play a larger than life role in the lives of self-managing people. We definitely don't want to be known as "the bad patient".

I acknowledge daily that I have a huge advantage in reaching the level of self-management, being a nurse for over 40 years. I know what newly-diagnosed patients and families might not know—not just because I understand basic anatomy and physiology, but I have also learned the importance of consistency, self-advocacy, and the ability to set up reliable clinical systems and responsive networks. I also know there are many people who will never get to self-management expertise because of zero to minimal resources, health literacy barriers, issues with cognition, disabilities, mental health and substance abuse problems, and/or worse: having no one in their lives that loves or cares for them. Some people have actually burned all their bridges for receiving help.

For those people engaged in getting help but only beginning the journey to self-management, the good news is that Medicare and other payers are beginning to reimburse for care coordination and case management services. This is a positive innovation, and many will arrive somewhere on the self-management spectrum. However, every healthcare professional can give you names of people from their caseloads who will never achieve self-management and will constantly require multiple, expensive interventions.

I know, because it takes every ounce of self-management skill not to need those interventions myself.



THE CENTER FOR CASE MANAGEMENT

QUIZ: How Much Do You Know about Chronic Illness/Conditions?ⁱ

True or False?

1. A “trajectory” is defined as the course of an illness over time, plus the actions of clients, families, and healthcare professionals to manage that course.ⁱⁱ
2. Patients that have the same exact illness (same diagnosis based on pathophysiology) have the same illness trajectory.
3. To be effective, the case manager for a person with chronic illness should learn how to create an “insider–expert” relationship with the patient.ⁱⁱⁱ
4. The goal of coaching people with chronic illness is to help them be totally compliant with physician orders and directions.^{iv}
5. According to CMSA’s (Case Management Society of America) Case Management Standards, people receiving case management from private case managers and payers must give permission for that service.
6. Warfarin is the medication that is the cause of the most Emergency Room visits.^v
7. DRGs that are coded and billed as MCCs (such as DRG 435 “Disorders of Hepatobiliary System or Pancreas W MCC”) are more highly reimbursed by Medicare than DRGs that have no MCCs (such as DRG 440: “Disorders of Hepatobiliary System or Pancreas W/O CC/MCC”).^{vi}
8. Chronic conditions are almost always terminal, which is why they must be managed as aggressively as possible.
9. A person’s family is the best judge of their loved one’s change in the quality of life caused by chronic illness because they are more objective than the patient his/herself.
10. Diabetics diagnosed with even minor depression have higher HBA1c levels than diabetics without depression, even when the population is adjusted for demographics, co–morbidity, severity, diabetes type and duration, treatment type, and clinic.^{vii}
11. Depression has no effect on the amount of cardiac risk factors in diabetic patients.^{viii}
12. The top 5% of complexly ill patients use 50% of the US health resources.^{ix}
13. According to Milliman Healthcare (2006), patients with cancer have the highest prevalence of mental conditions when compared with other patients, such as those with COPD, neurological disorders, and heart disease.^x
14. People who rate their own health as “Fair to Poor” are more likely to be high healthcare service users than those that rate their health as better than Fair.^{xi}
15. The main challenge of training COPD patients how to care for themselves is that the prolonged and persistent hypoxia have deteriorated their lung function and reduced their cognitive performance.^{xii}
16. Community Lifecare Planning (CLP) is the process of creating a medical plan of care with a chronically–ill and/or handicapped person and their family.^{xiii}
17. Because patients with high complexity are often uninsured or underinsured, receiving comprehensive care is not as likely to occur as for patients with high quality insurance coverage.^{xiv}

18. In 2007, the nonprofit Center for Studying Health System Change found that 25 million adult Americans sought new primary care doctors, and more than 60 million sought new specialists.^{xv}
19. Various expert medical committees usually agree on guidelines, evidence, and “Best practice for the treatment of chronic illness”^{xvi}
20. The most helpful advice that can be given to a burned-out family caregiver is to remind him or her to get enough rest.

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ⁱ 1) T, 2) F, 3) T, 4) F, 5) T, 6) T, 7) T, 8) F, 9) F, 10) T, 11) F, 12) T, 13) F, 14) T, 15) T, 16) F, 17) T, 18) T, 19) F, 20) F

ⁱⁱ Corbin, 1998 in Lubkin and Larsen, *Chronic Illness*, MA: Jones and Bartlett, p 3.

ⁱⁱⁱ Lamb, G. and Stempel, J., “Nurse Case Management from the Client’s View: Growing as Insider-Expert”, *Nursing Outlook* Jan/Feb 1994, p 7-13

^{iv} Hamilton, G.

^v The Remington Report (March/April 2012) Vol. 20, No. 2. P 8; CDC Report in [NEJM](#)

^{vi} Ingenix DRG Expert, 2012

^{vii} Kathol, R., Perez, R., and Cohen, J. (2011) *The Integrated Case Management Manual*, NY: Springer, p.23

^{viii} *IBID* p. 22

^{ix} *Ibid*, p. 16

^x *Ibid* p. 16

^{xi} *Ibid*, p. 12

^{xii} Messenger, R. “Reducing COPD Readmissions”, *Professional Case Management*, 2012, p 109

^{xiii} Jackson, J. *Healthcare Without Medicare*, Lenox, MA.

^{xiv} Kathol, R., Lattimer, C., Gold, W, Perez, R., and Gutteridge, D. *Professional Case Management*, Vol. 16, No 6, p. 290-298

^{xv} Ha T., Tu and Lauer, J *Word of Mouth and physician referrals still drive health care provider choice*”, HSC Research Brief, December, 2008

^{xvi} Groopman, J, and Hartzband, P. [Your Medical Mind](#). NY: Penguin Books, 2011, p 62

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