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Adaptive Leadership Framework for Chronic Illness

Framing a Research Agenda for Transforming Care Delivery

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We propose the Adaptive Leadership Framework for Chronic Illness as a novel framework for conceptualizing, studying, and providing care. This framework is an application of the Adaptive Leadership Framework developed by Heifetz and colleagues for business. Our framework views health care as a complex adaptive system and addresses the intersection at which people with chronic illness interface with the care system. We shift focus from symptoms to symptoms and the challenges they pose for patients/families. We describe how providers and patients/families might collaborate to create shared meaning of symptoms and challenges to coproduce appropriate approaches to care. **Key words:** *adaptation, chronic disease, complex adaptive systems, complexity science, delivery of health care, leadership, professional-patient relationships, self-management, symptoms*

PREDICTIONS are that over the course of history, few pandemics will lead to

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as much suffering and premature deaths as the global epidemic of chronic disease, the leading cause of death and disability worldwide. It impacts people of all ages^{1,2} and without concerted action, some 388 million people worldwide will die of chronic non-communicable diseases between 2007 and 2017.³ Chronic illness takes a tremendous toll globally on fiscal and health care resources.⁴ Western medicine, often held as a model, is very good at providing care to people with acute or curable conditions but has struggled with models of care for those with chronic conditions.⁵

People with chronic illness experience symptoms that are complex, multicausal, and nonlinear.⁶ These symptoms create disability and burden for individuals^{7,8} and families,⁹ and significantly impact their lives¹⁰⁻¹³ by influencing the ability to meet developmental milestones across the lifespan,¹⁴ and the ability to work or attend school.¹⁵ Adaptation in chronic illness does not follow a predictable

path from diagnosis through recovery because people with chronic illness and their families often must accept certain symptoms and/or disabilities impacting multiple life domains, such as energy, vitality, ability to carry out activities of daily living, and relationships with family and friends. Patients must “tackle mental suffering as well as physical suffering,”^{12(p A12)} involving loss and grief as functional or cognitive levels change.^{12,16} These ambiguous trajectories of chronic illness might immobilize patients and families, preventing development of new behaviors or reorganization of roles.¹⁷ Thus one real impact of chronic illness lies in the symptoms that people must live with, learn to adapt to, and compensate for in their daily lives. These are significant areas for developing new care models.

A paradigm shift is needed in the care of people with chronic illness because the previous focus on curative, provider-centered care has led to an emphasis on technical care such as surgery or medications; for example, using bariatric surgery or weight loss medications, without enough attention to the fundamental changes in patient behavior necessary to sustain weight loss. New models of care, such as the medical home and the chronic care model, have been designed to transform care to be patient-centered but the transition has been quite difficult.^{5,18} In identifying the grand challenges associated with chronic illness, Daar et al³ identified reform of professional training and modification of health systems as essential. To help accomplish such reform, new conceptualizations and research agendas are needed to better understand how patients might interface with the care system to promote adaptation to chronic illness.

In this article, we apply the Adaptive Leadership Framework, developed by Heifetz et al¹⁶ for the business and management field, which has been used in areas such as organizational change,¹⁹ leadership, and supervision.^{20,21} We have applied this novel framework to chronic illness to examine symptom trajectories and the challenges they

raise for patients, families, and health care providers and propose new areas for patient-centered research and practice. Our approach guides individuals and their formal and informal care providers to work collaboratively toward symptom management and/or adapting in ways that facilitate optimal functioning. Thus the Adaptive Leadership Framework for Chronic Illness addresses current limitations in how we understand management of chronic illness. First, our Framework addresses the fundamental interactions between patient, family, and providers, and second, it addresses the trajectory of the illness and its management over time.

Of note, there are many existing theories with which to frame research and practice about adaptation to chronic illness, such as the common sense model of illness representation,²² transformative learning and response-shift theory,²³ self-regulation theory,²⁴ transtheoretical model,²⁵ and stress and coping,²⁶ to name a few. The framework we propose does not supplant existing theories; rather, it expands the perspectives for conceptualizing, studying, and providing care in chronic illness. Our work is grounded in complexity science,²⁷ and thus we have applied Heifetz et al’s framework to chronic illness using a complex adaptive systems’ perspective.²⁷ Because of the proposition in complexity science that interactions and relationships are the basis for the outcomes that emerge,²⁸ we were guided to focus on relationships between providers and patients/families and how they might collaborate to create shared meaning of symptoms and challenges and to coproduce appropriate approaches to care. We shift the focus on symptoms to a focus on symptoms *and* the challenges they pose for patients/families. The role of the provider expands from “doing for” as a technical expert to “doing with” and requires skills for helping patients and families develop capacity to adapt and address their challenges and then supporting their new skills as they do their adaptive work. In this way, the collaborative team coproduces care. Finally, given the holistic view of

complex adaptive systems, we were guided to address the intersection at which people with chronic illness interface with the care system.

THE ADAPTIVE LEADERSHIP FRAMEWORK FOR CHRONIC ILLNESS

We propose our framework, derived from Heifetz et al's Adaptive Leadership Framework, as a guide to the study of trajectories of changes in chronic illness symptoms and for developing better tools for providing patient-centered care. The Adaptive Leadership Framework for Chronic Illness aligns with key features of patient-centered care; both aim to give patients a voice in care decisions that are also shaped by individual or family preferences and values.²⁹⁻³¹ However, once treatment decisions are made, most discussions of patient-centered care do not extend to working *with* patients once treatment decisions are made, keeping patients at the center, and helping them to develop capacity to adapt to difficult challenges and develop new behaviors needed to manage their health situation over the trajectory of their chronic illness. Berwick³² considers this type of care "bold" but necessary to high quality care. The Adaptive Leadership Framework for Chronic Illness guides researchers to develop the evidence base for extending patient-centered care through and beyond treatment decisions by focusing on the relationship between patient and provider as they co-manage chronic illness over time.

The Adaptive Leadership Framework, as proposed for management and business,¹⁶ suggests that problems and challenges arise from differing contexts. Technical challenges are such that the problem can be defined and an expert can be found with the know-how to solve it using expertise. Waiting times and scheduling are examples of technical challenges in health care clinics. Adaptive challenges are such that the problem requires a response that is not within the current repertoire of the individual or group with the chal-

lenge. How to address "patient-centeredness" in health care is an example of an adaptive challenge for providers. For adaptive challenges, the gap between goals and current capabilities cannot be closed by expertise alone. The person who owns the adaptive challenge is the one who must do the adaptive work.

In Figures 1 to 4, we use color to represent roles and continuums. We use yellow for technical challenges and technical work, green for adaptive challenges and adaptive work, and blue to indicate that providers will address both technical and adaptive challenges and employ both technical and adaptive care approaches.

Figure 1 shows our attempt to depict the framework as proposed by Heifetz et al.¹⁶ The Adaptive Leadership Framework suggests that for many problem contexts, challenges likely range on a continuum from purely technical to purely adaptive with most situations having some combination of technical and adaptive challenges, meaning that some aspects will be technical and some will be adaptive. Experts (providers with prescription pad; consultants with a "solution") can address technical challenges using existing solutions but only the person with the adaptive challenge can address the adaptive challenges. Adaptive leadership, according to Heifetz et al, is the ability to distinguish between technical and adaptive challenges and the ability to align approaches. Adaptive leaders must have skills for facilitating technical work with the application of expertise. For adaptive challenges, they must guide their workers in developing

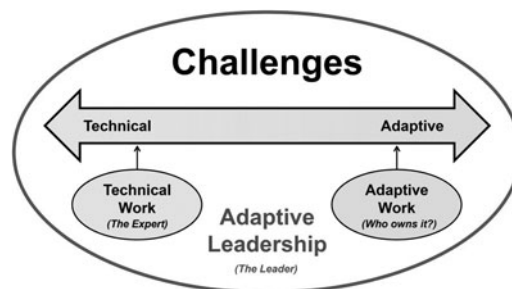


Figure 1. Our interpretation of Heifetz et al's Adaptive Leadership Framework.

new skills and capacities because the person or group with the challenge owns the adaptive challenge; thus, adaptive leaders facilitate them to do the adaptive work needed. Adaptive leaders have the knowledge and wisdom to help individuals and teams to identify challenges and accurately sort them as technical or adaptive, find the right experts to bring in solutions, and most importantly support team members in developing adaptive capacity—skills needed to close the gaps created by the adaptive challenges. Adaptive leaders need not be managers or administrators; they might arise anywhere in the system.

Next, we apply Heifetz et al's framework to chronic illness care. In our application to chronic illness, we explicate the intersection between chronic illness and the care system to reflect a new lens for addressing chronic illness research and practice. By intersection, we mean the points at which a person interacts with the care system, such as a clinical encounter with a provider. To explicate the intersection, we describe the model piece by piece to demonstrate how the nature of chronic illness might be addressed using the Adaptive Leadership Framework for Chronic Illness. It is useful to recognize people as complex adaptive systems that continually adapt both physically and psychologically as they interact with the environment³³ and that they are nested within a hierarchy of complex adaptive systems such as families and the care clinics.²⁷

Chronic illness dynamics

At the most fundamental level of the model (Figure 2), we depict that symptoms in chronic illness do not follow a predictable path from diagnosis through recovery and, unlike acute illness, full recovery seldom occurs. As shown in Figure 2, patterning of symptoms in chronic illness are dynamic and unpredictable; symptoms intermittently emerge then wax and wane, and then might plateau,³⁴ sometimes for no apparent reason. This aspect of the model draws attention also to the longitudinal nature of the symptoms

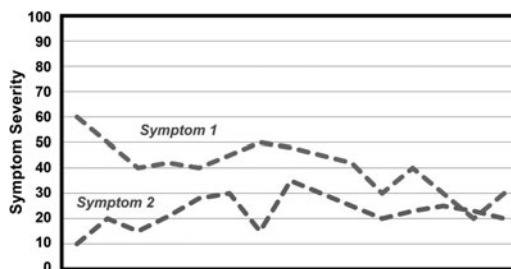


Figure 2. Chronic illness dynamics.

of chronic illness. Rolland³⁵ describes 3 basic trajectories that might occur in chronic illness, each raising different implications for the individual/family living with the illness. Progressive disease, such as Alzheimer's or pulmonary fibrosis, will have a trajectory of generally increasing or stepwise patterns of progression in illness severity, symptoms, and disability over time, which will require continual adaptation to new issues or limitations as they arise. Illnesses with a constant course begin with an acute event after which the individual will establish a new but relatively stable picture for long periods of time, for example, myocardial infarction or spinal cord injury. In illnesses with a constant course, individuals and families have longer periods in which to adapt before facing new symptom dynamics and/or development of increased disability. Finally, Rolland described a third trajectory as relapsing or episodic, such as epilepsy, migraines, or mental illness, in which symptoms wax and wane frequently and unpredictably. This trajectory pattern requires individuals and families to move back and forth between types of adaptive work.

Dynamics of technical and adaptive challenges

Similar to symptom dynamics, adaptation in chronic illness does not follow a predictable path, as shown in Figure 3. Technical and adaptive challenges will fluctuate as symptoms wax and wane over the trajectory and thus adapting in chronic illness is continuous, varied, and must be exercised

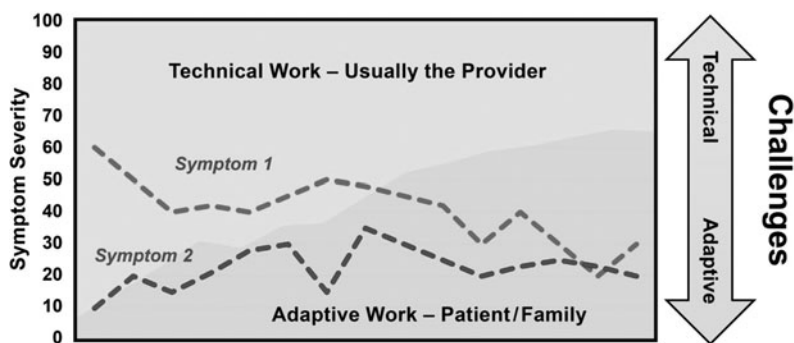


Figure 3. Dynamics of technical and adaptive challenges.

over time.¹² The Adaptive Leadership Framework for Chronic Illness guides researchers to classify patient challenges as those that the provider, as expert, would address (ie, technical challenges) and those that *only* the patient and/or family caregiver can address (ie, adaptive challenges) but for which they might not currently possess the capability. Because challenges arise in the life context, a goal in the Adaptive Leadership Framework for Chronic Illness is to identify, in collaboration with patients, which challenges are technical and which are adaptive. This requires development of shared meaning of the challenge and knowing the patient's current capacities for adapting. The evidence-base is well formed for technical approaches that reduce or eliminate symptoms and/or their sequelae, for example, medications for anxiety, modifying the texture of food to facilitate mealtime for cognitively impaired people, or managing hydration to improve cognitive status following stroke. As such, technical approaches are familiar to providers (eg, nurses, physicians, or other clinical professionals), and patients have learned to expect that technical solutions will be delivered. However, most challenges encountered by patients with chronic illnesses are adaptive in nature, such as, how to take opioid medication for pain symptoms while attempting to return to work. Providers might inappropriately use a technical approach when adaptive work by the patient or family would be optimal for better outcomes; this

oversight occurs in part because providers do not have access to evidence to guide them in assessing adaptive challenges, patients existing adaptive capacity, or interventions to facilitate patients' adaptive work. Thus, we assert that in health care, the primary focus has been on technical care; adaptive challenges and associated work often have been ignored. Patients intersecting with the health care system have come to expect and even desire these technical fixes. Thygeson³⁶ provides many examples of the overuse of technical approaches and underuse of adaptive approaches, such as using proton pump inhibitors for heartburn. Because these drugs actually induce heartburn in healthy research subjects, they often lead to long-term use that will perpetuate the symptoms; neglected are the needs for adaptive changes such as diet and positioning.

The Adaptive Leadership Framework for Chronic Illness guides researchers to focus not only on the patient's technical challenges but also on the adaptive challenges created by a patient's, and/or their family's, responses to the illness and its symptoms. The framework focuses attention to situations for which the patient/family lacks capacity to do adaptive work. For example, patients undergoing chemotherapy might experience mild cognitive impairments, such as processing speed, working memory, visual memory, and verbal memory and this might interfere with their ability to multitask in ways that they normally would in their home, school, and work

life^{37,38}; these patients will need to develop new ways to manage tasks. Throughout our discussion, we use the term of patient to refer to individuals across the life span. Individuals at very young ages and very old ages might rely more on families to do adaptive work. Similarly, individuals with moderate to several cognitive impairments will also rely more on families to do adaptive work. In situations where families are doing adaptive work, it is in response to the challenges they face such as developing new care giving skills or learning to adapt to their family members' level of need.

Collaborative work and adaptive leadership

Next, we add collaborative work to the model (Figure 4). We define collaborative work as work that providers and patients/families do together. The figure depicts that, given the nature of chronic illness, the collaborative work necessary for adaptation occurs over time and is relationship-based. Relationship development and management are aspects of collaborative work. Given that chronic illness involves dynamics, an aspect of collaborative work is monitoring. However, monitoring symptoms also includes how the patient and/or family respond to the symptoms. For example, 2 people reporting the same level of fatigue might have very different responses because of their life context. One person might be able to schedule a nap during the workday, whereas a shift worker would not be able to accommodate higher levels of fatigue at work. Clinical measures might provide a starting point for understanding symptoms but to fully assess them requires developing a shared meaning of the challenges that the symptoms create for the patient/family within their life context. Thus availability of tools for monitoring symptoms needs to be expanded to include ways to identify the challenges that arise for the patient and/or family; these challenges often pertain to their particular response to symptoms within their own context.

As shown in Figure 4, assessing challenges and existing capacities to address challenges requires exchanging information and creating shared meaning of the patient's challenge. Knowing what the challenges are and what meaning they hold is essential to learning what approaches to use for either technical or adaptive interventions. For example, people undergoing triple therapy for Hepatitis C, with interferon, ribavirin, and a protease inhibitor, will experience severe symptoms such as fatigue, cognitive impairment, and labile mood. In a case study of 8 patients in this type of treatment, researchers found that 2 men dropped out of treatment early, not because of the severity of symptoms, but because of the toll the symptoms were taking on their ability to maintain their family roles.³⁹ Interviews with the patients revealed that the symptoms created an adaptive challenge in which the patient expected himself to maintain his usual family roles and he perceived he was disappointing them. The provider never explored this with the patient and the patient did not bring it up in encounters; thus, the provider did not understand the meaning of the symptoms to this patient. If the provider had probed to gain this understanding of how symptoms were impacting this patient and family, he/she would have been able to go beyond a purely technical approach to symptom management by discussing with the patient and family ways to adjust the family roles for the duration of the treatment. Doing this might have avoided the discontinuation of therapy, and instead assisted the family to adapt to the loss of the father/husband as they knew him. Working collaboratively, the patient, family, and provider might have identified ways to adapt the home life and environment to support temporary changes in roles and expectations. Thus, gaining a shared understanding of how the patient and/or family respond(s) to the symptoms is essential to knowing how to plan care together.

Thus, as suggested in Figure 4, patient and family responses create the adaptive challenges and suggest the work that patients or families must do to manage symptoms.

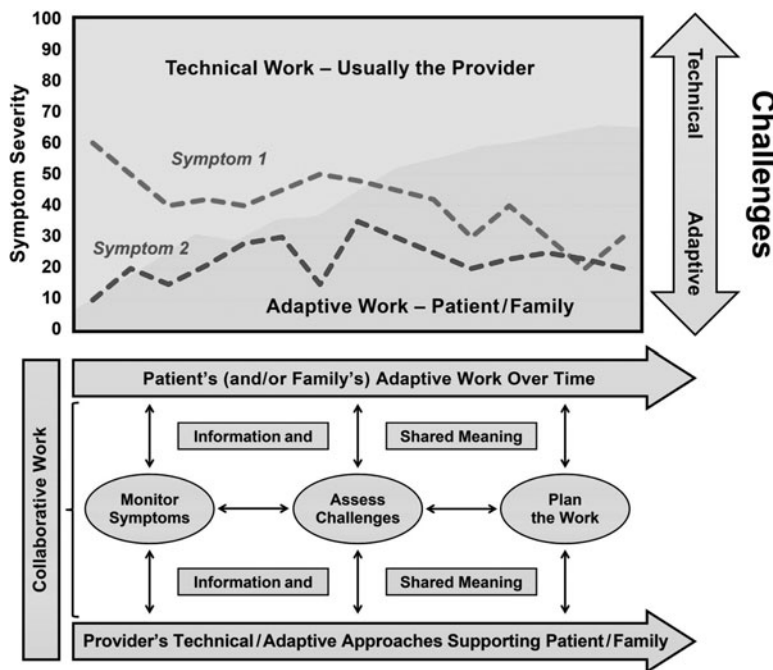


Figure 4. The Adaptive Leadership Framework for Chronic Illness.

Simultaneously, there usually is technical work that a provider can do to alleviate symptoms. Jointly, the provider and patient/family plan the work that each will do, over time, to enhance care; each is involved in monitoring and sharing symptoms and symptom responses as they change over time. The 2-way arrows suggest that the interactions between the patient/family and providers require a trusting relationship in which the patient can share concerns, feel that they are heard and be empathetically understood by providers. When this occurs patient/family and providers develop a shared meaning of the patient/family's responses to challenges, and assess the personal skill and psychological resources the patient/family already has to engage in adaptive work and how the provider might support them in developing new skills needed for adaptive work. In the Adaptive Leadership Framework for Chronic Illness, providers and patient/family collaborate to coproduce care, that is, patient and/or family caregivers are full partners in their care.

Adaptive leadership in the context of chronic illness care systems

Anyone on the collaborative team (eg, patient/family and providers) might assume the role of adaptive leader by identifying adaptive work for oneself or others and encouraging adaptive change. Adaptive leadership typically involves recognizing a challenge, taking initiative to set up and lead conversation; thus anyone in the team might demonstrate this leadership. Providers demonstrate Adaptive Leadership behaviors when they recognize the limits of technical approaches, work in partnership with the patient/family to define the challenges, and then identify strategies (adaptive work) to address these challenges. Although not addressed in this particular framework for chronic illness, providers must take responsibility for making their own adaptive changes when needed.³⁶ For example, learning to practice using adaptive leadership approaches would likely require that many providers do adaptive work to learn to collaborate with

patients and families, gain skills in assessing adaptive challenges and capacities, and begin creating and implementing adaptive interventions.

To summarize what adaptive leadership means in chronic illness care, we assert that the aim of adaptive leadership is to facilitate the patient/family to do the work necessary to close the gap created by adaptive challenges by encompassing a holistic approach to patients within their life contexts.^{33,40} Adaptive leadership requires patients/families and providers to gain new knowledge and skills thus increasing their adaptive capacity, so that they can move beyond their present repertoire to achieve the clinical outcomes they desire. Adaptive leaders take initiative to engage in collaborative work with patients/families, gain shared understanding, and jointly develop care plans to address adaptive challenges (which might be owned by patient, family members, provider) created by the clinical situations in which they find themselves.

DISCUSSION: AREAS FOR RESEARCH DEVELOPMENT

The Adaptive Leadership Framework for Chronic Illness is ideal for advancing novel areas for research.⁴⁰ Here, we pose some areas for innovative research by walking again through the components of our model. Specifically, we discuss the implications of symptom dynamics, collaborative work, adaptive work, and adaptive interventions.

Symptom dynamics

The Adaptive Leadership Framework for Chronic Illness highlights the need for studies that develop a deeper understanding of trajectories of symptoms including patterns, variability, and change over time in relation to other unique personal characteristics. This knowledge will bring key insights about critical time periods or transition points, differences within subpopulations such as minority or low income, and provide

a starting point for developing interventions to enhance patients' adaptive capabilities. Despite the time-dependent nature of the symptom experience and distress, and symptom sequelae in chronic illness,^{12,34} studies typically have been cross-sectional or include only short-term outcomes of disease-specific symptoms, cognitive/affective changes, responses of patients and family, or management skills.⁴¹⁻⁴³ To support adaptive work that addresses adaptive challenges requires that we understand sequelae and the temporal patterns in symptoms, and how patient/families and providers collaborate to assess the challenges associated with these symptom trajectories. This type of research is critical for developing a new generation of interventions to ameliorate symptoms, symptom distress and to address symptom responses in chronic illness using adaptive approaches. Some research questions to explore might include the following:

- What technologies track symptoms in real time to create meaningful trajectories of symptom dynamics in response to behavioral and environmental changes and or life events?
- How might we develop patient-centered measures and family-centered measures of adaptive challenges that arise from symptom trajectories?
- What new understandings do providers gain about adaptive challenges from viewing symptom trajectories versus point-in-time measures?

Collaborative work

Collaborative work depends on the nature and quality of relationships between providers, patients, and family members. Thus, we begin our discussion of research about collaborative work with ideas about relationship building and management and how relationships might develop to achieve jointly informed monitoring of symptoms, assessment of challenges and capabilities, information exchange, development of shared meaning, and planning work. Then we address research implications for

adaptive work and adaptive approaches and/or intervention.

Relationship building and management

Most prior research has focused on patients and their families with little consideration of relationships between patients/families and providers.⁴⁴ The Adaptive Leadership Framework for Chronic Illness suggests that research is needed to guide providers and patient/family about how to develop relationships that facilitate shared understandings over time of the adaptive challenges created by the impact of the symptoms across multiple life domains as well as the existing adaptive capacity and/or need for new development of skills. Prior research highlights areas in which interactions between providers and patients/families might interfere with adaptive approaches. For example, Wood et al⁴⁵ found that providers struggled to believe the level of symptom distress expressed by patients with cardiac arrhythmias. Similarly, Granger et al⁴⁶ found that while both patients and providers perceived self-management adherence to a heart failure regimen as “work,” patients perceived it as “hard” whereas physicians perceived it as easy-to-follow instructions. Granger et al⁴⁷ also found that nurses rated patients as having enough information about medications when the same patients reported a need for more information. Such inconsistency in patient and provider understanding of patient challenges will likely mean that providers will not effectively address symptoms common in chronic illness. Tulsy⁴⁸ previously tested a successful intervention to help providers develop the types of interactions and shared meaning that are depicted in the Adaptive Leadership Framework for Chronic Illness. It is clear that much more research is needed to guide providers in how to develop shared meaning and jointly plan care. Some questions to explore might include the following:

- What strategies might be developed to improve both the provider and patient and family ability to communicate and engage in joint problem solving?

- What approaches might effectively help providers, patients, and family to develop and manage relationships in clinical encounters?
- What skills and/or assessment tools are needed to help providers, patients, and families develop shared meaning about the nature of challenges?

Implications for adaptive work

The Adaptive Leadership Framework for Chronic Illness suggests types of research that will be fruitful in promoting adaptive work by patients experiencing symptoms of chronic illness. Frequently used prior approaches have been to modify the distressing aspects of symptoms and reduce the need for behavior change. However, many aspects of chronic illness do not have technical solutions and patients must learn to adapt to the difficult challenges; thus they own the work that needs to be done to address the challenge. Some examples of this type of adaptive work are dealing with the loss of old habits and behaviors to make room for new behaviors, changing life style, cognitive reframing, symptom management strategies, and engaging in treatment such as developing systems to promote medication adherence and adherence to exercise regimens prescribed by physical therapists. Some questions to explore might include the following:

- What assessment strategies and tools might be developed to assist patients and providers in identifying patients’ adaptive work and evaluate its effectiveness?
- What existing self-management theories are useful for addressing adaptive work?
- How might collaborative work between patients, families, and providers include allocation of the work to be accomplished?

Implications for interventions to address adaptive challenges

The concepts of the Adaptive Leadership Framework for Chronic Illness, as discussed earlier, suggest a variety of new areas for

intervention development. The model guides researchers to develop and test ways to assess the existing adaptive skill set of patients/families and then help them develop new capacities that are still needed to fully address their challenges. Along this line, Tulsy is engaged in an innovative intervention study⁴⁹ in which cancer patients are learning skills needed to actively communicate their concerns to providers, supporting our idea that patients/families can develop the capacity to fully collaborate in the work with providers. Adaptive interventions might be created to help people shift from passive to active work in their own self-management. For example, Hudson et al⁵⁰ identified that African American women used mainly passive strategies, such as faith or acceptance, to manage menopausal symptoms, and urged providers to develop more active strategies, which we would call adaptive work. Adams et al⁵¹ identified adaptive challenges faced by families as they consider transitioning a loved one from curative to palliative care. Even in extreme cognitive impairment, there is some capacity of people to adapt and gain a sense of authority over care. For example, Aselage⁵² is testing different techniques for feeding individuals with severe dementia and hypothesizes that a superior approach stimulates well-established muscle memory for feeding oneself and promotes a sense of control over the feeding activity, thus tapping remaining capacity for adaptive work. Some questions to explore might include the following:

- What interventions are needed to help patients reframe their health beliefs to gain positive control over aspects of the illness and/or their responses to them?
- When symptoms cannot be lessened by technical approaches, what interventions might help patients adapt to pain, other symptoms, disability, and/or end of life?
- How do we design interventions to facilitate adaptation by people with cognitive and affective changes that so often accompany chronic illness?

A caveat: Providers and healthcare system also have adaptive work

An important area for new intervention development relates to providers and the care system. Many providers will face adaptive challenges when they begin engaging in adaptive leadership because it will require them to do the adaptive work of changing attitudes, beliefs about roles and gaining new skills not in their current toolkit. When difficult, but frank, conversations are needed with patients, for example, to address issues such as end of life⁵³ or clarifying the limits of the medical approaches and the work that the patient must own, providers might engage in work avoidance, a term coined by Thygeson et al.³³ Even though Strauss et al⁵⁴ introduced the notion of patients' work and the need to explicitly divide "labor" between providers, patients, and family in 1985, the concept of patient work is still not well-recognized and is not part of most provider-patient interactions. "Explicitly acknowledging patients' work on behalf of their own health clarifies that patients are part of the health care team . . ." ^{33(p1012)} Thygeson³⁶ explores the difficulties that physicians and other providers have in doing the adaptive work needed to become adaptive leaders. He suggests that interventions for providers should address issues such as work avoidance (ie, avoiding difficult discussion with patients/families), developing adaptive leadership skills, improving communication skills, and improving shared decision-making skills among others. Some related research questions might be as follows:

- What tools might providers use to identify their own adaptive challenges related to being an adaptive leader in chronic care encounters and organizations?
- What adult learning strategies would be best for helping providers gain effective skills for collaborative work with patient and families?

The care system itself faces adaptive challenges because it must change to facilitate patients and providers in addressing adaptive

challenges. People in the United States are familiar with the 10-15 minute appointment model in primary care, which may not allow time for relationship development needed for collaborative work between patients, families, and providers. Given that the financial structure of the health care system is not likely to change quickly, researchers can be helpful in developing and testing innovations to improve collaborative work within the current constraints of the care system. Some related research questions might be as follows:

- What health care system changes are needed to support providers as adaptive leaders?
- How can information technology reduce time currently spent by the provider interacting with the computer rather than the patient/family?

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SUMMARY

Novel paradigms are needed for care of people with chronic illness to disrupt the current global pandemic of chronic illness's extreme morbidity and increasing mortality. The contemporary Western system of reliance on curative, provider-centered care has led to an emphasis on, and an expectation of, technical care and a de-emphasis on adaptive work necessary to self-manage. The Adaptive Leadership Framework for Chronic Illness is a novel conceptualization for chronic illness management that does not supplant existing theories, but it serves as a tool to shift focus of care to identifying adaptive challenges and collaborating to plan the adaptive work that can only be done by the person with the illness and/or his or her family.

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