

Continuing care of chronic illness: Evidence-based medicine and narrative-based medicine as competencies for patient-centered care

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Abstract: The longitudinal care of patients with chronic illnesses is one of the most central responsibilities of a family physician's practice. To the patient-physician relationship, the patient brings his needs – arising from his prior life experiences, current life situation, resources, and explanatory models of illness. The physician brings expertise and evidence about the best care for the disease. The bridge connecting these two worlds is narrative-based medicine (NBM). An essential competency for the best care of patients with chronic illness is an amalgamation of evidence-based medicine (EBM) and NBM, based upon an underlying infrastructure of behavioral science. Although such knowledge, skills, and attitudes are essential, the very best longitudinal care develops over time and requires careful observation by physicians.

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Introduction

In Japan family medicine is not yet recognized as a specialty. Therefore, a certification system for family physicians has not been developed. Until recently, there were few academic departments focusing on general medical practice. However, in recent years the Ministry of Education, Culture, Sports, Science and Technology, which is responsible for undergraduate medical education, has supported the establishment of departments focusing on general medical practice, usually called Department of General Medicine. Currently, approximately half of the 80 medical schools in Japan have Departments of General Medicine. These departments serve as an academic base for physicians who teach and conduct research in family medicine.

During this initial period of the founding of these departments of general medicine, there has been considerable confusion about the role of generalist physi-

cians. Popular conceptions of generalist physicians encompass family physicians, general internists, and emergency medicine specialists. While it may seem strange to those from countries where primary care is well-developed, few people in Japan, even within medicine, understand that these three specialties require different clinical competencies. This has been a source of confusion; family physicians are not clearly differentiated from other specialists.

Continuity of care is the one ideal that perhaps most distinctively differentiates family physicians from emergency medicine specialists. Other fundamental characteristics of primary care, such as accessibility, comprehensiveness, coordination, and accountability can be characterized as shared ideals. Thus, here I would like to focus on continuity of care for patients with chronic illness and the attendant required clinical competencies.

Competencies required for care of chronic illness

Evidence-based medicine

What might the clinical competencies required for care of chronic illness be? To take the best care of the

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patients with chronic illness, we must practice evidence-based medicine (EBM), defined as ‘the conscientious, judicious and explicit use of current best evidence in making decisions about the care of individual patients.’¹ For example, tight control of glucose should be encouraged for patients with diabetes, even if it is cumbersome or inconvenient because the evidence clearly shows that they will thereby have a better quality of life in the long run. To stay abreast of the current evidence, we must be familiar with how to access the relevant evidence and stay attuned to current guidelines for various commonly encountered chronic illnesses.

One aspect of EBM that receives comparatively little attention is that genuine evidence-based practice presuppose an *interpretive paradigm*, within which the patient experiences illness and the clinician-patient encounter is enacted.² Compared with other types of medical care, in the continuing care of chronic illness, a mutually respectful and intimate clinician-patient relationship, within which illness is understood as a unique human experience, is of paramount importance. The knowledge, skills, and attitude necessary for understanding illness as a unique human experience are characterized by Greenhalgh and Hurwitz as narrative-based medicine (NBM).²

Narrative-based medicine

Illness is the realm inhabited by the sick person, whereas disease categories are often quite crude maps that health professionals use to interpret the sick person’s experience, from the other side of the wellness-illness divide.² As Ian McWhinney writes,³

‘It is not easy for us to attend to our patients’ experience. To do so requires us to step out of our usual way of attending to a person’s illness. We are trained to see illness as a set of signs and symptoms defining a disease state – as a case of diabetes or peptic ulcer or schizophrenia. The patient, on the other hand, sees illness in terms of its effects on his or her life. The physician therefore must learn to see illness as it is lived through, before it has been categorized and interpreted in scientific terms.’

To account for each patient’s story as an individual one is an extremely important clinical competence in the care of patients with chronic illness. If the clinician does not possess this competency, the most up-to-date, evidence-based knowledge of the clinician cannot be put to good use, for it is often compromised by poor adherence on the part of patients. Studies show that only 50% of patients being treated for chronic conditions are taking their medications as prescribed at any given time; and only 10 to 35% of patients follow through with recommended lifestyle changes.⁴

Nonadherence is often a reflection of inadequate attention to making care patient-centered.

For example, a diabetic patient may have sufficient knowledge about the diet and exercise recommended for her, but feels unable to adhere to them because of the stress that she feels from her mother-in-law living with her family. This patient sees eating as the only outlet for her stress. Typically, a clinician might urge better adherence to the diet and exercise regimen, drawing upon the evidence that this will improve her glucose control. However, without an understanding of the patient’s lifeworld, including her social situation and her core values, the clinician might find that all his blandishments are useless. To elicit the reasons for her nonadherence and understand the sources of her stress, the clinician must be receptive, empathic, and attentive in listening to her story.

Further, this entails a relationship-centered (in contrast to a physician-centered or patient-dominated) approach.⁵ Such an approach integrates the perspectives of both patient and physician and acknowledges that both have unique interests and contributions to make to the care process. The patient brings his needs based on his experience, situation, resources, and explanatory model. The physician brings expertise and evidence about the best care of the disease. In a relationship-centered approach, power is shared. The encounter is negotiated to reflect the interests, concerns, and needs of each participant; physician and patient collaborate in defining the goals and methods of treatment. Thus, an attentive and relationship-centered approach is an important aspect of NBM.

Behavioral sciences – the intellectual infrastructure for the care of chronic illness

In addition to the competencies of EBM and NBM, I would like to emphasize a third competency essential for the successful care of patients with chronic illnesses. This is the ability to provide care for the psychological aspects of patient’s illnesses. This competency consists of knowledge of behavioral science and skills in communication. Chronic illnesses can affect people’s lives tremendously, often entailing significant changes in areas such as daily activities, sexuality, emotional responses, and relationships.⁶ Chronic illnesses can cause a variety of emotions such as denial, anger, depression, and anxiety, though not all people experience such emotions, and not always in a particular sequence. For example, we often encounter patients whose depression needs to be alleviated first in order to make possible proper control of chronic illness. Practitioners caring for patients with chronic illness need to be attuned to such commonly encountered emotions and equipped with effective intervention skills.

Conclusion

In summary, to care for patients with chronic illnesses, physicians must have competence in EBM and NBM as well as competence in behavioral medicine. Acquiring such competencies can be said to be the learners-centered task necessary for a biopsychosocial approach to medicine. However, the very best care for patients with chronic illness goes even further, beyond such cognitive (knowledge), psychomotor (skill), and affective (attitudinal) competencies. Indeed, understanding of a patient's existential situation – deriving from longitudinal interaction between the physician and the patient and his family – is perhaps what is needed to

truly respond to the patient's needs and truly satisfy both parties. It is difficult, however, to turn such a goal into a learning objective for trainees, for such relationships can only be developed over time and requires careful observation on the part of the physician.

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