Making the case for the study of symptoms in family practice

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The evaluation and, when possible, alleviation of symptoms is a substantial portion of the work of family physicians. However, until recently, it has received relatively little research attention.[1,2] That is changing owing to 2 factors: large databases derived from anonymized, aggregated data from electronic medical records (EMRs), and a coding system that allows for recording the reason for encounters, including symptoms.

Role of symptoms and their frequency in practice

Evaluation of symptoms—the patient's expression of their experience of illness—is a key part of the work of family physicians and others in primary care. Community studies show that, in any given month, 80% of people experience symptoms; 33% consider seeking care and 22% actually visit a physician.[3,4] In their role as first-contact practitioners, family physicians tend to see symptoms earlier in the process than is the case with referral-based practitioners, and, as a result, undifferentiated symptoms are a substantial part of the work in primary care, present in 50% to 60% of visits.[5,6] Symptoms, when combined with signs and investigations, might lead to a new diagnosis; they might represent a repeat presentation of a pre-existing diagnosis; or they might remain undiagnosed (medically undiagnosed symptoms). Nevertheless, even when a diagnosis is made, symptoms frequently continue. At least one-third of common symptoms do not have a clear-cut disease-based explanation, and although many improve over weeks to months, 20% to 25% will become chronic or recurrent.[6] Family physicians are challenged to make early diagnoses of serious illness, and when faced with unexplained symptoms, physicians tend to order more tests in pursuit of a diagnosis.[7] The ability to evaluate an undifferentiated symptom and make an early diagnosis of a serious illness is a hallmark of excellent clinicians and one of the ways in which family medicine improves health system functioning.[8] Symptoms are predictive of health care use, quality of life, work-related disability, and mortality.[6] In a world where multiple chronic diseases are the norm in clinical practice,[9,10] diagnoses are usually known and the role of symptoms goes beyond assisting in the diagnostic process, and symptoms require attention in their own right to address patient suffering. Therefore, evidence-informed evaluation of symptoms is critical to effective medicine improving 2 of the Triple Aim agenda items: the patient experience and being efficient with resources.[11]

Why have symptoms not, in the past, received much attention?

In spite of their importance, research on symptoms dwindled during the first half of the 20th century.[1,2] Research has been hampered for several reasons. The first is the lingering effects of the dominant medical model that emerged in the late 19th century. In this model, illness was conceived of as being due to discrete disease entities that existed separate from the individual sufferer. This led to studies to identify and describe the natural history of various diseases in the 19th and early 20th centuries.[12] Combining the symptom with objective physical signs, bolstered by results of laboratory and imaging investigations, completed the diagnostic process. Over the 20th century, emphasis on the location of the disease "in the body"[13] and the emergence of increasingly powerful imaging and laboratory investigations heavily tilted the diagnostic process away from symptoms toward "objective" findings. This has added to the cost of medical care, as clinicians attempt to fit patients' symptoms into known diagnostic categories. Diagnostic categories provide names for patients' illnesses, thereby reducing anxiety and uncertainty, and, ideally, they provide direction to optimal treatment and prognosis and are part of the infrastructure of health care necessary for many bureaucratic and administrative purposes, as well as for epidemiologic research.

The second key barrier to doing research on symptoms is their inherently idiosyncratic nature. They can be highly nuanced and particular to the patient, and in any given medical practice will be present in too few patients to make systematic inquiry feasible.

Return to focus on symptoms

Since the late 20th and into the early 21st century, several developments have changed these dynamics. First, there has been an increased emphasis on patients' illness experience, the subjective aspect of ill health. This has involved developing an understanding of illness in the context of the patient's life and is one of the key elements of the patient-centred clinical method.[14] It has been argued that, rather than symptoms being seen as a derivative of disease, they should be recognized as a higher-order phenomenon, blending elements of disease and nondisease, and, therefore, "the most human expression of clinical medicine,"[6] deserving to be the focus of research in their own right.[15]

Second, the widespread use of EMRs makes possible anonymized aggregations of many individual encounters in different medical practices, thus increasing the number of cases available for study.[16-19]

However, to be useful for studying symptoms, such data must use standardized coding systems, such as the International Classification of Primary Care,[20] which includes codes for symptoms as well as diseases. When used in its

entirety (coding all reasons for encounters and procedures, and all end-of-visit codes), it provides a more complete picture of activity in family practice than is available from health administrative data. The analytic power possible with the combination of large EMR databases and standardized coding holds the promise of providing new insights unique to family medicine.[21] Symptoms and the pathways they follow over time can be linked to patient characteristics and social variables to place illness in its full context.

Returning to our roots

Recently, it has been recommended that, in family and general practice, symptoms be accepted as equivalent to diagnoses when they are a more accurate description of the level of clinical certainty.[22,23] Knowledge of the prognosis of symptoms might reduce the imperative to initiate investigations, attempting to fit the patient into an abstract category of disease taxonomy. Symptom-based prognosis, in some ways, hearkens back to the traditional meaning of *diagnosis*, which referred to the person, rather than a disease label.[24] But if symptom-based prognoses are to be useful, there must be knowledge of the natural history of symptoms. Over years of practice, family physicians tend to acquire such knowledge tacitly, but younger physicians have no access to this experiential knowledge. Studies of natural history are needed, not just of diseases, but of symptoms.

Necessary elements of research on symptoms

A broad-based program of research on symptoms is recommended.[25] It needs to recognize that symptoms are often multiple, usually multifactorial in cause, and frequently occur in recognizable clusters.[26,27] Both patient characteristics (age, sex, demography, concurrent disorders, psychological and social factors) and symptom characteristics (severity, location, duration, accompanying symptoms) need to be taken into account. Broad prognostic categories of symptoms (self-limited, symptom disorder, recurrent or persistent)[23] have been suggested and might help to define a research program. For example, those symptoms that are chronic or recurrent hold greater interest for family physicians. Defining the pathways or natural history of recurrent, persistent symptoms is a necessary first step.

However, a moment's reflection will make clear that not all of what is needed to be known about symptoms is contained in large, well-coded databases. There remains a need for studies closer to the lived world of the patient. Symptom studies are ideal for mixed-methods research including case studies, case series, qualitative studies, and linguistics.[28-30]

In Canada, there is a long, but interrupted, history of studying the frequency of presenting symptoms in general in family practice[31] and of specific symptoms such as headache,[32] chest pain,[33] urinary symptoms,[34] and fatigue.[35-37]

With the expansion of EMRs and the availability of coding systems that include symptoms, it is an opportune time to once again engage in symptom research that is uniquely relevant to daily family practice.

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Competing interests

None declared

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