

## Extract

# Mental health classification in primary care

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### KEY MESSAGES

- We need a system of classification to help us make sense of the variety of mental health problems found in primary care.
- Mental health classification systems in primary care cannot simply be drawn from those used in psychiatry. The ways in which problems are presented and understood by patients, and the options available for management, are often very different from those found in specialist settings.
- In addition to accurately defining the diseases that may or may not be present, we need tools for classification that address problems and illnesses experienced by those seeking care, the clinical and social context in which those problems occur, and patients' personal preferences, goals and priorities for care.
- A valid primary care mental health classification must capture the dynamic interaction between these factors as it unfolds over time.

## Introduction

Since 1980 we have seen the introduction of several classifications of mental health disorders intended for use in primary health care. This list began with the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) and has continued through DSM-IV and DSM-IV-PC (Primary Care), the 10th edition of the International Classification of Diseases for Primary Health Care (ICD-10-PHC), and the International Classification of Primary Care (ICPC-2). Development of the 'next generation' of primary care mental health classifications is now under way, with work on ICD-11-PC, DSM-V and ICPC-3. Despite considerable efforts at harmonisation, there are significant differences in how each of these tools covers the clinical domain of mental health problems.<sup>1</sup>

These differences reveal our lack of understanding about the process of emotional suffering and its

relationship to the development of mental disorders, and reflect a fundamental difference between primary care and specialty mental health professionals in the perceived importance of social and cultural factors in understanding and formally diagnosing mental disorders. We seem to be able to agree on a set of criteria to diagnose hypertension, or diabetes, and these biomedical classification standards have been relatively stable over time. But we cannot agree on a stable set of criteria for 'depressive disorder': The DSM, ICD, and ICPC definitions will each capture a different group of patients suffering from depressive symptoms,<sup>1,2</sup> and we cannot even agree whether anxiety and depression represents one disorder or two!<sup>3,4</sup> What is the problem here? Why have our definitions changed so much in recent years,

and why do such differences persist between our major classification tools?

## Why do we need mental health classification at all?

The short answer is that *classification is necessary to order a clinical domain*. The ordering principle(s) used to create a classification depend on the boundaries of that domain, as well as the planned uses of the classification. For us, the clinical domain is *primary healthcare*, so the classification needs to include the full range of mental health problems experienced by persons who seek care in this setting. There are several potential uses for an international classification that covers the domain of mental health problems.

- We need an international classification for *mental disorders*, so that professionals from different parts of the world can communicate between themselves and know exactly what disease they are discussing, or what type of pathology a patient is suffering from. This uniformity is especially important when treatment, including the development of new therapeutic strategies, is involved. For disorders for which treatment guidelines are created, the definition of the disorder needs to be precise and reproducible.
- A classification of mental disorders is also necessary in order to conduct research. If we want to conduct international research into the prevalence of specific disorders or conditions, we must start with a common view about how those conditions are defined.
- A classification of mental disorders is important to the efficient organisation of health systems. Payment for consultations and other type of interventions needs to be based on the type of problems addressed, so that treatment (and its payment) can be effectively managed for a defined population.
- We also need an international classification of *mental health problems* that do not qualify as mental disorders (or diseases), so that professionals can communicate clearly between themselves and know exactly what types of problems are being managed, for both clinical and research purposes. This is of particular importance to the domain of primary healthcare, as problems such as 'feeling anxious' or 'feeling depressed' are not the same as a 'subthreshold' or 'minor' mood disorder, and may have different clinical pathways over time.<sup>5,6</sup>

## Problems with classification

The last point above points out one of the major difficulties in primary care classification: the issues or problems that lead patients to seek medical consultation involve much more than diseases. Examples include routine check-ups and physical examinations, feeling distressed or overwhelmed with personal problems, experiencing somatic symptoms for which there is no clear medical diagnosis, and a long list of interventions for disease prevention and health promotion. It is very important that systems designed to be used in primary care to classify existing diseases also provide a way to classify issues or problems that bring people in to consult with health professionals in the absence of a specific disease. Both ICD-10 and ICPC include non-disease codes: ICD-10 has a list of social problem and preventive care codes, and ICPC offers a comprehensive list of symptoms, preventive care and social problem codes. Even where there is full domain coverage (diseases, problems, other issues), classification systems share several general problems.

### Defining disease

The first problem is simply defining a 'disease'. In simplest terms, a disease is what somebody has when they get sick. That may well be true in many cases, but it leaves a lot of room for error at the margins.

### Category or continuum

The conventional approach to defining diseases assumes that you either have or do not have a condition. This works reasonably well for infectious diseases such as tuberculosis, or for acute medical problems such as myocardial infarctions. It does not work very well for most mental health problems, as these are based on common sensations and perceptions that most of us experience from time to time.

It is apparent that the various symptoms that make up the diagnostic categories of mental disorders are distributed widely and variously across the population. We all feel anxious, or low in mood from time to time, and many of us have occasional thoughts about suicide, or wonder if other people are behaving suspiciously towards us. It is also demonstrable that our experience of these symptoms can change quickly, sometimes within a matter of hours or days. Any cut-off in the level or duration of symptoms which is taken to represent a 'true' diagnosis is therefore bound to be arbitrary.

So, at what point do a particular group of symptoms emerge as a clinical, pathological or psychiatric disorder? As Rose and Barker succinctly express it: 'the real question ... is not "Has he got it?" but "How much of it has he got?"'.<sup>7</sup> Classification must here involve an arbitrary element, in finding an agreed-upon point along a continuum to label as a disorder. For example, in the classification system adopted in DSM-IV, at least two from a set of nine symptoms have to be present for at least two weeks to qualify for a diagnosis of minor depression, and at least five from the same set for two weeks to qualify as major depression. But the rationale used to make these arbitrary decisions on symptom counts and duration is not clear. Why not three symptoms for minor depression, or six for major depression? Why two weeks' duration? Why not ten days, or three weeks?

Rose and Barker describe four possible solutions to this problem. First, a decision to award clinical status to a condition or set of symptoms may be made on statistical grounds, for instance if they are more than two standard deviations from the age-specific mean of a particular population. Second, clinical status may be granted when a set of symptoms or complications becomes more frequent. Third, a 'prognostic' or functional approach awards clinical status when a particular level or amount of something is more likely to cause problems than having a different level or amount of that something. Fourth, an 'operational' or utility-based approach awards clinical status to levels of symptoms above which action will improve either symptoms or prognosis. The developers of DSM, ICD and ICPC have used a combination of these methods to define mental health disorders. However, only ICPC has used statistical evidence from the primary care setting in setting its definitions.

### *Alternative versus biomedical models*

Another way to approach definitions for diseases or disorders is to consider different theoretical models for understanding health and disease processes. The biomedical model has dominated scientific research and mainstream medical care for many years, while the alternative medicine model (acupuncture, homeopathy, others) appeals to many who see the shortcomings of biomedicine.

The biomedical model considers that pathophysiological changes are the basis on which to consider and characterise the presence of a pathological process. These changes can be seen directly, or inferred on the basis of a medical history, biomedical imaging or laboratory testing. From this point of view, diseases represent something going wrong within our body that we need to find and fix.<sup>8</sup> The alternative medi-

cal model holds that getting sick is just a problem of one's own imbalance; symptoms and diseases simply demonstrate that the internal equilibrium was lost. The problem is not just that there is a part of the body that needs repair, but rather that the whole person is not well and should be given assistance in recovering their health (equilibrium).<sup>9</sup>

All three mental health classifications (DSM, ICD, ICPC) are based upon the biomedical model, listing specific disorders associated with specific changes in pathophysiology. Some effort has been made to map biomedical mental health disorders to traditional or alternative medicine disorders, but this work is in its early stages.

### *The problem of validity*

Disease categories should only be regarded as valid if they can be shown to be discrete entities with natural boundaries that separate them from other disorders.<sup>10</sup> These boundaries may be based on observable differences in symptom clusters, or on specific neurobiological pathways or genetic patterns.

Despite historical and research assumptions to the contrary, there is little evidence to support the contention that currently recognised mental disorders are separated by natural boundaries. Variation in symptoms is continuous between the different mental disorders, and between mental disorders and normality.<sup>11</sup>

Taking depression as a prominent example, a careful examination of its apparent diagnostic boundaries reveals a high degree of uncertainty, disagreement and confusion.<sup>12</sup> This is most apparent in attempts to distinguish between depression and anxiety disorders. There is a view gaining ground within psychiatric circles that anxiety and depression should be regarded as two symptomatic presentations of a common broader underlying vulnerability, or of a common affective disorder, within which the expression of anxiety or depressive symptoms may vary over time.<sup>13</sup> This is supported by the high prevalence of depressive symptoms in patients with anxiety and vice versa,<sup>14</sup> and the strong correlation between anxiety and depression when measured by research rating scales.

There is also considerable overlap of symptoms between common mental and physical disorders. For example, in chronic obstructive pulmonary disease (COPD), somatic symptoms such as fatigue, anorexia and weight loss may be simultaneously attributable to both the medical condition of COPD and the psychiatric diagnosis of depression. This raises substantial risks of diagnostic confusion, particularly in primary care where mental and physical problems frequently coexist.

Even more uncertain are the boundaries between anxiety, depression and somatisation in primary care. There is now a considerable amount of empirical evidence suggesting that persistent medically unexplained symptoms frequently coexist with mood or anxiety disorders. This coexistence may be cross-sectional in that all these symptoms appear together at the same time,<sup>15</sup> or it may be longitudinal in that one set of symptoms is followed closely in time by another.<sup>16</sup>

Nor has the quest for neurobiological markers of specific mental disorders had great success. Although some studies have indicated a link between the serotonin transporter (5HTT) gene and depression in the context of adverse life events, these findings have to be interpreted with caution. Positive linkage of effects tends to be over-reported in small samples, and the combined analyses of multiple datasets, including a larger number of candidate genes and polymorphisms, will be necessary for an adequate assessment of the presence and impact of depression susceptibility genes (see Chapter 2).<sup>17</sup>

There is already evidence that genetic variations are related to generic rather than specific vulnerability. Associations have been found, for example, between short variations of the 5HTT gene and predisposition to alcohol disorders,<sup>18</sup> and perhaps schizophrenia.<sup>19</sup> These findings indicate an overlap in genetic susceptibility across the traditional classification systems for mental disorders.

### *The problem of utility*

Mental health disorders may be 'valid' but not useful in clinical practice. Conversely, even 'invalid' diagnoses may possess high utility by virtue of the information they convey about aetiology, outcome or treatment response.<sup>2</sup>

However, the argument that a diagnosis is useful on the grounds that it offers a rationale for providing or withholding treatment is increasingly open to question. As one example, growing evidence for a substantial placebo effect in treating major depressive disorder suggests that the rationale for active treatment with antidepressant medication is not as strong as previously believed.

In a review of 75 double-blind placebo-controlled trials of antidepressant medication for adults in ambulatory care, Walsh and colleagues found the placebo response to be 'variable, substantial and growing'.<sup>20</sup> Kirsch and colleagues have analysed antidepressant medication data submitted to the US Food and Drug Administration. Using the Hamilton Depression Rating Scale as their benchmark, they found that the mean overall difference between responses to antidepressant drugs and placebo in this database was two points: although this differ-

ence was statistically significant, it is well below accepted levels of clinical importance.<sup>21</sup> They subsequently found that drug-placebo differences increase in relation to initial severity, with conventional criteria for clinical importance reached only for patients at the upper end of the 'very severely depressed' category.<sup>22</sup>

The evidence for efficacy of psychological interventions such as cognitive-behavioural therapy is open to equal or even stronger challenge, on the grounds that their precise modes of action have not been adequately tested. Contextual factors, such as the impact of hope generated by an apparently scientific approach to treatment, the effects of therapist personality, or the benefits of time spent with a sympathetic professional, may be equally as important as, if not more important than, the specific formal components of a given therapeutic approach.<sup>23</sup>

### **Disease versus illness**

Another major problem in classifying mental disorders lies at the intersection of patient and caregiver. Kleinman,<sup>24</sup> Helman<sup>25</sup> and other medical anthropologists have shown that there are often substantial differences between what professionals, especially doctors, consider as disease and what patients mean by the same word. They have denominated these two distinct ways of understanding and representing the process of being sick as 'disease' and 'illness':

- *disease*: the biomedical conception on which professionals' understanding is based – scientifically based, measurable, involving an individual pathology that can be classified
- *illness*: the patients' perception of their suffering, which is subjective, culturally based and collective.

There is often a large gap between how patients understand and express their suffering and what professionals 'count' as symptoms associated with a disease. Patients may in practice be operating from a radically different image of what constitutes a medical problem. They may not consider their problems as being related to their mental health, or, even if they do, may not believe that they are worthy of medical attention.<sup>26</sup> In South Wales, for example, patients do not see problems relating to mood and social function as proper reasons to seek medical care: while it is reasonable to take signs and symptoms of a physical disorder to a doctor, they do not consider that this is the case for emotional distress.<sup>27</sup> From the professionals' perspective, trying to bridge the gap between patient symptoms experienced

during an illness and a specific disease that they can treat can lead to significant errors, and 'overtreatment' or 'undertreatment'.<sup>28</sup>

The central role of the patient in the therapeutic process has been determined quite recently, being the basis of new theoretical models underlying health interventions.<sup>29</sup> The movement from a disease-centred to a patient-centred approach is a recent advance for organised medicine, and corresponds to the increasing prevalence of chronic health conditions with a course and prognosis that is dependent on long-term management rather than curative treatment. For example, human immunodeficiency virus (HIV) infection has changed from a lethal disease in the 1980s to a chronic disorder in the 21st century. Successful management of chronic health conditions requires that the patient and provider reach mutual decisions about treatments that will continue over a long period of time, and those decisions must take into account personal factors such as illness beliefs, personal goals and preferences, behavioural activation and patient adherence. Unfortunately, our classification systems do not reach far enough into the 'patient side' to capture these factors,

The discrepancy between illness and disease is also affected by cultural patterns and the social context in which illness occurs.

### *Cultural patterns*

Cultural patterns may affect the expression or presentation of recognised mental health disorders, leading to confusion about their proper place in a classification. For example, neurasthenia and chronic fatigue syndrome appear at first glance to be distinct disorders, but a closer look reveals that they may represent the same pathological process, expressed in different ways in different cultures. The entire group of culturally bound syndromes present in DSM-IV can be questioned for the same reason. The term 'nerves' has been shown to be just a different way of naming and communicating a type of emotional distress that involves anxious and depressive reactions.<sup>30</sup> Medically unexplained symptoms can be considered a cultural way of presenting emotional distress, but can also be a core symptom of a somatoform disorder. The boundary between symptoms and distress on the one hand, and psychiatric disorder on the other, is one of the most debatable items in ICD-10 and DSM-IV.

More generally, cultural differences in perceptions of what a mental disorder might be can cause tremendous conflict between doctors and patients. For recent migrants or asylum seekers, distress may be deeply embedded within, and inseparable from, lives fraught with frightening premigration experi-

ences, traumatic escape and profound dislocation and alienation in their new 'home'. If a health professional tries to apply a rigid biomedical disease-based approach to depression in this situation involving a profoundly communal and structural account of emotional distress, problems are likely to occur.<sup>31</sup>

### *Context*

It is now well accepted that mental health problems arise out of a context that includes predisposing factors, social problems, life events and other circumstances. It is fair to say that context is involved in the causality, evolution and prognosis of mental health disorders. In primary healthcare, this context also includes the frequent presence of physical health problems and social difficulties. Patients very often see social problems as a major component of their reason for consulting their doctors, and find it impossible to disentangle them from how they are feeling. In everyday clinical practice, simply making a formal diagnosis of a mental health disorder is not sufficient to guide treatment decisions. We must know more. We need to know how severe the symptoms of the disease may be, how long it has lasted, and what levels of disability are associated with it.<sup>32</sup> We also need to know whether other social or medical problems are affecting the person we are trying to help.

Unfortunately, neither culture nor context has been routinely incorporated into any of our mental health classification tools. These aspects will be discussed in more detail below.

### *Classification problems specific to primary care*

As mentioned above, mental health disorders are often defined by an arbitrary cut-off point along a continuum of symptoms. For most disorders, the range of relevant symptoms and their cut-off points have been defined based on patients seen by mental health specialists in the United States (US) and similar western settings. While there is some evidence that core symptoms of depressive disorder may be equivalent in western and non-western settings,<sup>33</sup> the 'gold standard' for diagnosis generally does not accommodate the range of symptoms and severity experienced by persons in non-western settings, and it may not accurately reflect the range or severity of symptoms experienced by persons seen in western primary care settings.

Persons who present to primary care clinicians may be closer to 'normal' than those presenting to

specialists, and finding the correct cut-off point to differentiate normality from pathology can be quite difficult. For example, the set of nine cardinal symptoms for depressive disorder includes fatigue and sleep difficulties. These symptoms are predictive of depression in patients seen by mental health specialists, but they have a significantly lower predictive value in primary care – because the prevalence of severe depression is proportionately lower, and because fatigue and sleep concerns are prominent symptoms of patients with other health problems. So, even when DSM-IV or ICD-10 diagnostic criteria are correctly applied in primary care, some patients who ‘qualify’ for the label of major depression will have a less severe disorder, or no disorder at all.

It is still more difficult to determine ‘gold standards’ for problems with behaviour and emotions, where norms may differ across different cultures. How can the limit between normal sadness and the development of a depressive episode be defined for a mother who has lost a child? What is the normal level of anxiety expected for somebody who has lost a job and has no money to feed his family? Once again we go back to context, but when primary care is considered, these are urgent, everyday questions. The twin risks of medicalising normality, or of normalising illness processes, are always present.

Making sense of mental health suffering in primary care therefore demands special classification systems. It involves careful thought about the ways in which patients may experience and present their emotional distress, and how their physical and ‘medical’ symptoms may be mixed up with psychological symptoms. It also involves paying attention not only to the presence and severity of a core list of symptoms, but also to their chronicity, associated impairment, and the personal, social and cultural context in which those symptoms occur. Most importantly, it involves paying careful attention to the meanings that patients themselves may attach to their symptoms.

## Towards a new classification for primary care

With these issues in mind, we can see the need to redesign classification and terminology tools to more accurately capture the content areas needed to understand mental health conditions as seen in the primary care setting. These tools must address *problems and illnesses* experienced by those seeking care, the *clinical and social context* in which those problems occur, and patients’ *personal preferences*,

*goals and priorities* for care, in addition to accurately defining the *diseases* that may or may not be present. We will discuss each of these areas in turn.

## Diseases

We have described the limitations of disease-based classifications developed for specialty mental health care such as DSM-IV and Chapter V of ICD-10. While they provide a high level of diagnostic specificity, the criteria sets used for diagnosis are often of suspect validity in the primary care setting. Two ‘primary care’ diagnostic classifications, ICD-10-PC and ICPC-2, are increasingly used in primary care settings, but each has its limitations. ICD-10-PC was derived from the ‘parent’ ICD-10 and shares some of its validity issues, and ICPC-2 contains a limited number of relatively non-specific diagnostic terms. The conceptual overlap between ICD-10, DSM-IV and ICPC-2 is complex and incomplete, and mapping between these classifications has proven difficult.<sup>1</sup> None of the classifications in current use addresses diagnostic thresholds for disease ‘caseness’ or boundaries between disease categories in a satisfactory way for primary care, although ICPC provides a symptom-level alternative (for example, P03 – ‘feeling depressed’) to assigning a ‘minor’ or ‘subthreshold’ case the label of ‘depressive disorder’.<sup>34</sup>

Work is currently under way to develop the next generation of primary care disease classifications, ICD-11-PC and ICPC-3. These parallel efforts are being co-ordinated so that core diagnostic content is more closely aligned, to improve clinical validity and utility, and to improve their mapping to the more granular specialty-based classifications. These revised classifications should provide improved coverage of this core content area.

## Problems and ‘illnesses’

Patients in primary care present with problems (or illnesses) until such time as their problems are given a disease label. In many cases, a formal diagnosis of disease is never made – a common situation in primary healthcare, but one that cannot be accommodated in disease-based classifications! We know that illness behaviour is not always associated with disease; therefore, it is absolutely essential that a primary care mental health classification be able to reliably capture and track problems that have only a ‘symptom’ label, or problems that are not related to the presence of a specific disease.

This capability is a core feature of ICPC-2, which includes a set of rubrics describing common emotional

symptoms (such as 'feeling anxious', 'acute stress') that can be used to capture the patient's reason for encounter or as the 'diagnosis' at the end of the encounter. ICD-10 contains some symptom-level 'diagnosis' codes scattered across chapters, but these codes provide incomplete coverage and are infrequently used. The multi-axial nature of the full DSM-IV diagnostic classification encompasses a variety of biopsychosocial parameters, but the psychosocial content is only a modifier for a formal 'disease' diagnosis.

### Clinical and social context

Our current classification tools have limited capacity to capture clinical and social problems, events or circumstances that can influence or cause mental health problems. Chapter XXI of ICD-10 contains some social problem codes, but these are incomplete and rarely used. Chapter Z of ICPC-2 includes a number of common social and personal problems that may be a reason for either encounter or a diagnosis, but use of these rubrics has also been limited. We have not developed classification or terminology tools to capture personal demographics, cultural beliefs, or other social determinants of mental health or care-seeking behaviour.

Much work is needed to fill in the gaps in this content area. While ICPC-2 offers the best current coverage of symptoms and problems, further work to develop content such as a 'cultural beliefs' classification or terminology is needed.

### Personal preferences, goals, and priorities

In the setting of multimorbidity and increasing prevalence of chronic health problems, the delivery of person-centred health care requires that clinicians understand and respect the goals, priorities and preferences of their patients. For patients with mental health problems, it would be important to know whether patients prefer, or reject, pharmacological treatment for depression – or whether they rank management of their mental health symptoms or problems as a higher or lower priority than their other health problems. If known, these preferences would clearly affect treatment and enhance clinician-patient relationships.

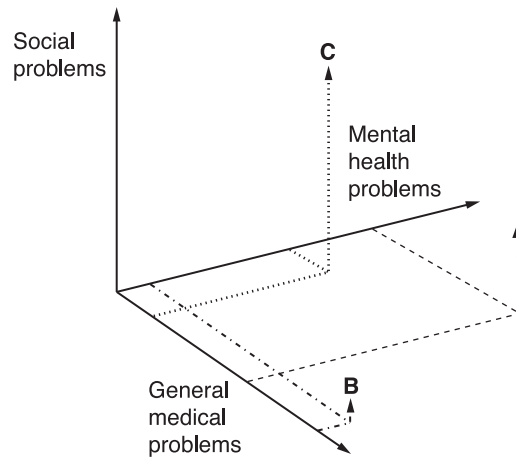
We have not developed a system to reliably capture and use patient preferences and goals in primary care; this area remains a high priority for future research.

## Putting it all together: classification and terminology tools in a primary care data model

We know that primary care patients frequently present for care with a mixture of psychological, physical and social problems. When we view primary care through a 'disease' lens, we first look at the primary 'disease', then see other problems that we artificially label as 'comorbid' and of secondary importance. But mental health and general medical comorbidities, along with social problems, are the rule rather than the exception in persons coming to see primary care clinicians, and they are certainly not of secondary importance in the process of care. Our understanding of primary care might be enhanced by replacing the term 'comorbidity' with 'multimorbidity' and focusing effort on the integration of diagnosis and treatment across biomedical, mental health and social domains,<sup>35–37</sup> in a three-dimensional biopsychosocial space. In this space, the severity or level of problems in each domain at a single point in time could, in theory, be plotted as a point on an axis (see Figure 1), as a rough estimate of the overall burden of illness. Over time, the position of the point on each axis will change.

As the biopsychosocial model would predict,<sup>38</sup> these three domains are highly correlated. Mental health problems are known to occur more frequently in those with common chronic physical illness, such as diabetes, arthritis and heart disease;<sup>39–43</sup> general medical conditions affect how persons experience and cope with their mental health problems,<sup>44–46</sup> and the presence of social problems or the occurrence of significant life events has a major impact on the severity of mental health problems or outcomes of care for chronic physical illness.<sup>47,48</sup> Over time, changes in the severity of general health problems may create additional social problems or intensify existing mental health problems, and increasing severity of mental health problems may amplify physical symptoms. Understanding and managing these interactions is a core part of the everyday work of a primary care physician.

*A valid primary care mental health classification must capture this dynamic interaction as it unfolds over time.* Viewed through this integrated lens, and coupled with knowledge of patients' preferences and goals, we will be better able to understand the effectiveness of mental health care provided in the primary care setting. A group of primary care leaders in the US has produced a first draft of a data model to support the 'patient-centred medical home'.<sup>49</sup> The model, shown in Table 1, includes each of the content areas discussed above, within its seven core components.



**Figure 1** The three-dimensional matrix of primary care diagnosis

**Point A** characterises a person with a moderate level of general medical problems, a high level of mental health problems, and a fairly low level of social problems.

**Point B** characterises a person with a 'classic' biomedical illness: a high level of general medical problems, a low level of mental health problems, and a minimal level of social problems.

**Point C** characterises a person with a low level of general medical problems, a moderate level of mental health problems, and a very high level of social problems.

- *Patient background*: demographic, social, and geographic information, not currently captured in a standard format.
- *Active problems*: health problems currently known to and being addressed by the healthcare team. In a model that adheres to the episode structure, each active problem has a 'history' tracing its path from initial reason for encounter (first point of contact with the health system) to current status. This feature enables the calculation of specific disease probabilities for presenting symptoms as well as the proportion of symptoms that resolve without formal diagnosis.
- *Clinical modifiers*: previously experienced clinical events or risk factors that are important to the care process but are not active clinical problems. Examples include significant medical events (hysterectomy, cerebrovascular accident) and known risk factors (genetic, biochemical or historical).
- *Patient goals, preferences and requests*: patients' expressed goals, priorities and preferences for care, limits to care (advance directives), and the reasons why patients choose to seek care.
- *Process data*: capturing the decisions made in the course of care; laboratory or ancillary services, referral decisions, procedures performed, pharmacy orders, exception or error reporting and follow-up plans.
- *Time (and the episode structure)*: organising data longitudinally, for example, following the structure of the episode of care, enables clinical data to be placed in the context of time. Without this structure, clinical data lose much of their meaning and validity.
- *Information-exchange protocols (data interoperability)*: enables structured import and export of data between electronic health records to assist in co-ordination of care across settings.

Here is one patient example (from the practice of MK) to illustrate the importance of capturing and integrating information from all three domains.

When viewed through a medical lens and from the data available in our electronic health record, 'appropriate' care was provided to MM during her hospital admission and 'inappropriate' care was provided after, as we did not formally diagnose and aggressively treat a major depressive episode. Viewed through a biopsychosocial lens, *and from the perspective of the patient*, her hospital stay was unnecessary and created harm through additional use of narcotic analgesics, while her follow-up care met her expressed needs. In the absence of available data on clinical modifiers (concerns about business) and patient goals (maintain function, solve business problems and avoid medication), we cannot see – or assess – the proper treatment path for MM.



**Table 1** Content available for the primary care data model

Components	Available content
Person (background)	ICPC (limited); ICF (limited)
Demographics	
Social structure	
Functional status	
Problem(s)	ICPC; ICD, SNOMED-CT; ICF (limited)
Current/active	
Severity	
Clinical modifiers	
ICPC (minimal); ICD (minimal)	
Prevention	
Risk factors	
Significant events	
Goals and requests	
ICPC (limited); ICNP (limited)	
Patient goals	
Patient preferences	
Requests for care	
Process data	ICPC (process codes); national procedure codes; ICNP; ATC; ICHI (in development)
Decisions	
Interventions	
Plans	
Time	ICPC
Episode structure	
Data import/export	
Exchange protocols	

ATC = Anatomical Therapeutic Chemical classification; ICD = International Classification of Diseases; ICF = International Classification of Functioning, Disability and Health; ICHI = International Classification of Health Interventions; ICPC = International Classification of Primary Care; SNOMED-CT = Systematised Nomenclature of Medicine – Clinical Terms.

**Box 1** Case Study

MM is a 54-year-old woman, a long-term patient with chronic medical problems including autoimmune pancreatitis, chronic abdominal pain, rheumatoid arthritis (RA), and osteoporosis related to long-term corticosteroid use to control RA. She has a long-term history of anxiety (with panic attacks) and depressive symptoms that wax and wane, sometimes meeting formal diagnostic criteria for a major depressive episode.

Her social history is complex and important to her current care. She grew up in a small town in the southern US in a family with prevalent substance abuse, depression and suicide. She was married at the age of 18 years but her husband died suddenly a few years later; she remarried several years later to a man who also struggled with substance abuse. She has a very strong work ethic and continued to work at physical labour tasks long after her RA became crippling, and now feels guilty that she cannot work at a paying job. She has at times been prescribed antidepressant medications, but is strongly opposed to their use because of her religious beliefs and prior experience of family members.

She recently presented to the emergency department with increased abdominal pain, and had a short inpatient hospital admission where her pain was managed with increased doses of narcotic analgesics. The hospital team did not identify the death of her second husband a few months earlier, and her increasing difficulties in sorting out his business affairs, as a primary contributor to distress and increased pain. Her pancreatitis was in fact in remission at the time of her admission. Over a series of encounters, we were able to identify and begin to manage her distress and anxiety as a first step in reducing her narcotic use, with the understanding that her primary short-term goal was simply to maintain function so that she could solve pressing business issues. Although she met formal criteria for major depressive episode when seen in follow-up, we considered this a ‘false-positive’ diagnosis related to recent life events and distress, and she responded well to supportive goal-focused care.

**What tools do we have? What tools do we need to develop?**

As seen in Table 1, much of the content in the primary care data model can be captured using

currently available classification and terminology tools. For some content, several options are available (for example, diagnostic content in the Systematised Nomenclature of Medicine (SNOMED), ICD

and ICPC). But in other areas, development is necessary. We do not yet know how to classify or record important *clinical modifiers* such as risk factors (genetic, biochemical or historical), and we have not made good use of existing classifications of social or personal determinants of health. We have not enabled patients to express and record their own goals or preferences for care. We have not captured process data related to mental healthcare, as much of it occurs outside the primary care practice, and data-exchange standards are not available.

Work is under way to close these gaps. The World Organization of Family Doctors (Wonca), World Health Organization (WHO) and International Health Terminology Standards Development Organisation (IHTSDO) are collaborating on the next generation of classification and terminology standards, and improving and harmonising the classification of social problems is a high priority. The Wonca International Classification Committee has begun work on a classification of risk factors and clinical modifiers to supplement ICPC. Discussion on how to best capture patients' goals and preferences has emerged in the past couple of years. Once these tools are available, we will be able to capture mental health in its real-world context in primary care practice.

In the end, the core task of general medical practice is to meet the needs of people living in communities. We must find a way to bring the patient's own voice into our work.

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