Capturing complexity: The case for a new classification system for mental disorders in primary care

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Abstract

Primary care differs considerably from specialist mental health settings: problems are presented in undifferentiated forms, with consequent difficulties in distinguishing between distress and disorder, and a complex relationship between psychological, mental and social problems and their temporal variations.

Existing psychiatric diagnostic systems, including ICD-10-PHC and DSM-IV-PC, are often difficult to apply in primary care. They do not adequately address co-morbidity, the substantial prevalence of sub-threshold disorders or problems with cross-cultural applications. Their focus on diagnosis may be too restrictive, with a need to consider severity and impairment separately.

ICPC-2, a classification system created specifically for use in primary care, provides advantages in that it allows for simple linkage between reason for encounter, diagnosis and intervention.

It is both necessary and feasible to develop a classification system for mental health in primary care that can meet four basic criteria: (1) characterized by simplicity; (2) addressing not only diagnosis but also severity, chronicity and disability; (3) feasible for routine data gathering in primary care as well as for training; and (4) enabling efficient communication between primary and specialty mental health care.

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1. The context of primary care

1.1. What is primary care?

Primary care is the ‘provision of integrated, accessible healthcare services by clinicians who are accountable for addressing a large majority of personal health needs, developing a sustained partnership with patients, and practicing in the context of the family and community’ [23]. Primary care systems can be categorized according to: whether they act as gatekeepers to specialist services (as in the UK), provide free-market services in parallel with specialist services, or function in a blended system containing both free-market and gatekeeper functionality (as in the US); whether free to patients at the point of care delivery; whether they are led by doctors or non-medical personnel; and the degree to which they provide continuity of care.

1.2. Complex presentations

People present to primary care with a wide variety of symptoms, concerns, worries and problems. The critical point is that primary care clinicians will often encounter
undifferentiated [4], unfiltered and unrecognized symptoms that may or may not be identifiable as mental health syndromes, while specialty mental health clinicians will more usually encounter filtered symptoms that are recognized and understood as representative of a mental health problem.

Many primary care patients are clearly distressed, but do not exhibit other symptoms of mental illness [28]: however primary care physicians may manage these patients differently than those without distress. They do so without guidance from existing nosological systems. The adverse consequences of the confusion between these two constructs can be seen in the misidentification of distressed patients as “depressed” by case-finding instruments such as the Center for Epidemiologic Studies — Depression (CES-D) scale or Hamilton Rating Scale for Depression (HAM-D) when they are employed in primary care [61,62].

Primary care patients frequently present a mixture of psychological, physical and social problems. The primary care context of life events and medical co-morbidity plays an important role in how patients experience their mental health symptoms [32]. Those symptoms reciprocally impact on subjective perceptions of health and objective measures of disease [65,67].

Even when primary care patients meet diagnostic criteria for specific disorders, their symptoms often fluctuate over time and their “caseness” may be transient [37]. There is an absence of research on the long-term validity and prognosis of threshold mental health diagnoses in primary care. Community-based epidemiologic studies have confirmed that many patients have recurrent or chronic depression [18,26,29,], but the relative risk of recurrence or chronicity in depressed primary care patients, and the level of disability associated with this risk, is not clear [78,79].

1.3. Clinical performance

The fluctuating nature of symptoms has made it difficult to assess the performance of primary care workers in recognizing and treating mental health problems. Recognition of their potential long-term impact on health and function has led to case-finding and treatment efforts in primary care settings to prevent disability. Although primary care workers have frequently been criticized for their lack of skill in recognizing threshold mental disorders, recognition in primary care is itself a complex phenomenon related in part to the transience of symptoms. Higher rates of detection (and treatment) have been found for patients with more severe symptoms and higher levels of disability [15,72], and there is evidence that short-term outcomes for “detected” and “undiagnosed” depressed primary care patients are no different [11].

2. The validity of existing diagnostic systems in primary care

Current classification systems are generally based upon research and experience in psychiatric settings. There is mounting evidence of important differences between patients seen in primary care and specialty mental health settings. Mentally ill patients in primary care are less distressed, less likely to have a discernible mental disorder, and be less impaired than their psychiatric cohorts [12,20,85]. Only a small minority of people across the world with mental health problems are treated in mental health settings [20]. This distortion compromises the primary care validity of classification systems based on patients seen in mental health settings.

2.1. Co-morbidity

Overlapping psychopathology exists along a spectrum of anxiety, depression, somatization and substance misuse in primary care. This co-existence may be cross-sectional in that all these symptoms appear together at the same time, or it may be longitudinal as one set of symptoms is followed closely in time by another [27].

The WHO Collaborative Study of Psychological Problems in General Health Care [77] found that well-defined psychological problems are frequent in general health-care settings: the most common co-occurrence was depression and anxiety [63]. There is considerable empirical evidence suggesting that persistent medically unexplained symptoms frequently coexist with mood or anxiety disorders in primary care settings [17,30,31,73]. Substance misuse may also commonly co-morbidity with anxiety and depression [42].

2.2. Sub-threshold disorders

Sub-threshold conditions are prevalent and associated with significant costs and disability. In the WHO study, 9% suffered from a sub-threshold condition that did not meet diagnostic criteria but had clinically significant symptoms and functional impairment [56]. The Australian National Survey of Mental Health and Well-being found considerable disability associated with symptom levels not reaching formal diagnosis of anxiety or depression [33]. In a US primary care study [54], sub-threshold symptoms were as common as their respective Axis I disorders for most major diagnostic categories, and associated with higher impairment than patients with no psychiatric symptoms. The scientific validity of a classification system in which the residual category (undifferentiated somatoform disorder) is far more common than the main subtype (somatization disorder) [24] is questionable.

2.3. Cross-cultural application of systems

The DSM-IV and ICD-10 classifications in current use are the direct descendants of clinical and research diagnostic classifications developed in the US and Western Europe. As such, they are based upon a Western conceptual framework of mental health and mental illness, and it is likely that some of their diagnostic categories have limited validity in other parts of the world. It is also likely that some conditions important in other, non-Western cultures have limited or inaccurate representation in DSM or ICD [45].
Support for this view comes from research which has demonstrated the following shortcomings: some formal diagnoses may lack concept validity in certain settings [55]; some ‘culture-bound’ diagnostic labels may not fit with formal diagnostic criteria, yet apparently serve a useful purpose in terms of describing a group with clinically significant levels of disturbance and disability [9]; severity thresholds for clinically significant diagnosis may differ between cultures [66].

2.4. Category, dimension or hierarchy

Categorical representation of important clinical phenomena can misrepresent dimensional qualities [22,46,68]. Application of particular hierarchical rules has implications for management in primary care. The diagnosis of adjustment disorder is undermined by mechanistic application of current DSM-IV criteria, to the point where it may be systematically removed from clinical consideration [8]. This is not just a semantic issue, since adjustment disorders are more likely than depression to be considered as self-limiting conditions, and therefore not in need of medical intervention.

2.5. Severity or impairment

There are two problems with the assumption that impairment is associated with severity. First, it downplays the impairment experienced by people with sub-threshold disorders. Second, it is contradicted by evidence that risk factors for depression and functional impairment are not identical [16]. This is particularly important in primary care. Since family doctors are better at assessing impairment than making psychiatric diagnoses, emphasis on this difference plays to the strengths of primary care.

3. Classification systems for primary care

3.1. Adapted classifications

Both DSM-IV and ICD-10 have been adapted for primary care. However, the extent to which these systems have been adopted into routine primary care data collection and monitoring across the world is unclear.

3.1.1. DSM-IV-PC

The primary care adaptation of DSM-IV was introduced in 1995 and contains a number of symptom-based clinical algorithms designed to guide the primary care physician through the diagnostic process [2].

Several limitations are evident [58]. While the multi-axial nature of DSM-IV encompasses a variety of biopsychosocial parameters, this is not emphasized in DSM-IV-PC. It is a large and complex volume that requires some level of familiarity before it can be used. Other general concerns include the need to validate its diagnostic criteria in the primary care setting [7], re-evaluate the relegation of sub-threshold disorders [57], and the need to connect diagnoses with specific treatments [13]. The child and adolescent version [81] did address the issue of sub-threshold conditions.

3.1.2. ICD-10-PHC

The primary care version of ICD-10 Chapter 5 for mental and behavioural disorders was published first in 1995 [76], and finalized after a series of field trials in different countries across the world [25]. It is now the most widely used system in primary care settings, as much for education and training as for data collection and coding. The classification is user-friendly and linked to management, including advice on drug and psychological treatments and information for patients [44]. The system consists of 25 conditions that are common in primary care settings, but each country is encouraged to adapt the system to its own needs.

However ICD-10-PHC does not address measurement of severity, associated disability or chronicity, nor the accompanying social problems manifest in primary care settings. It is also important to note that simply disseminating guidelines developed from ICD-10-PHC did not improve outcomes in a British primary care study [75].

3.2. ICPC

The International Classification of Primary Care (ICPC), first published in 1987 under the auspices of the World Organization of Family Doctors (WONCA), represents a departure from the two classifications described above. ICPC was designed to capture and code three essential elements of each clinical encounter: the patient’s reason for encounter, the clinician’s diagnosis, and the (diagnostic and therapeutic) interventions, all organized in an episode of care data structure that links initial to all subsequent encounters for the same clinical problem. This approach permits coding of 95% or more of primary care visits and enables the calculation of prior and posterior probabilities for important diseases [53]. Published experience with ICPC has confirmed the validity of its key elements [36,38,39,51] and its utility in creating and analyzing episodes of care for primary care problems [6,40].

ICPC-2 has been designed to be incorporated into electronic health record (EHR) software with a conversion map to ICD-10 [50,52,82]. The underlying data structure provides the backbone to the organization and retrieval of clinical data, and has been successfully tested in Australia, Europe and North America [5,47].

Although the limited diagnostic specificity available in ICPC is problematic, its advantage is its better capture of the context of mental health problems. The episode structure automatically accommodates co-morbidity by simply noting all active problems. The inclusion of symptoms as reasons for encounter enables investigation of the relationship between somatic symptoms and mental health disorders in a way not possible with other classifications. The routine coding of social problems (chapter Z) provides detail about the social context of mental health problems that is not available elsewhere.
4. Other tools used in primary care

4.1. Interview schedules

Interview schedules have primarily been used for research purposes. The exception is the PRIME-MD which has been widely used across the world and generates DSM-IV diagnoses [71]. However, it remains unclear to what extent such a formal schedule might be adopted into routine primary care consultations, particularly in developing countries. It could add more difficulties to the establishment of a good doctor–patient relationship, and restrict even more the approach to personal and social problems associated with the development of mental disorder, which are essential to the proper management of mental health problems, especially in primary care.

4.2. Screening tools

Screening tools have been widely used in research. The best known is the General Health Questionnaire [21], available in four versions and translated into numerous languages. The GHQ is non-specific and does not provide specific diagnoses unlike the HAD [83] (anxiety and depression) or the self-completion measures derived from PRIME-MD, the original comprehensive PHQ [69] and the depression-specific PHQ-9 [34], the GAD-7 for anxiety [70] and the PHQ-15 for severity of somatic symptoms [35].

There is uncertainty as to whether screening is of benefit in improving outcomes of psychiatric disorder in non-psychiatric settings [1,19]. A brief tool with two screening questions, plus a third inquiring if help is needed shows promise in terms of diagnostic validity [3]. But selfanswered questionnaires in underdeveloped countries usually have to be read by an interviewer, as a significant proportion of the patients attending primary care units are semi-illiterate [43].

4.3. Measuring severity

Screening questionnaires are also used to measure severity. The PHQ has been widely used for this purpose in depression, as have the Inventory to Diagnose Depression [84] and the Primary Care Screener for Affective Disorder (PC-SAD) [60]. All perform as well as the Beck Depression Inventory [59], although most have not been validated in languages other than English. Measurement of severity has been introduced in the UK through the Quality Outcomes Framework (QOF) in primary care, which enables assessment of severity to be linked to treatment guidelines for depression recommended by the National Institute for Clinical Excellence (NICE) [49].

4.4. Measuring impairment and disability

Disability in relation to depression has commonly been measured using the Sheehan Disability Scale [64], a three-item self-report scale measuring the severity of disability in the domains of work, family life/home responsibilities and social/leisure activities [41]. The Social Functioning Questionnaire (SFQ) was developed to meet the need for a quick assessment of perceived social function [74]. The World Health Organization Disability Assessment Schedule (WHO-DAS II) is a brief instrument which comes in a variety of versions for rating by observer, self or caregiver [80], which demonstrates consistency validity in primary care [10].

5. Revision of the classification systems

The planned revisions of ICD and DSM may better address primary care needs in two ways. First, it is likely that the new classifications will reflect a more “dimensional” than “categorical” approach; this should result in the classifications containing fewer highly specified disorders that require matching to long criteria sets. Second, it is possible that each will be constructed as a “telescoping” classification, with a basic set of disorders useful in primary care settings that extend to a more granular set of specific disorders useful in the specialty mental health sector.

Here is an example of how this might work. ICPC-2 contains unique rubrics representing about 30 specific mental health disorders. All but two of those 30 disorders can be grouped into one of six “diagnostic groups” (see Fig. 1) proposed for the ICD-11 mental health chapter: “internalizing” disorders (e.g. depression, anxiety, phobias), psychotic disorders (e.g. affective psychosis, schizophrenia), “externalizing” disorders (e.g. hyperkinetic disorder, substance abuse), neurocognitive disorders (dementia, organic psychosis), developmental disorders (e.g. autism, stammering/tics), and bodily function disorders (e.g. sexual dysfunction, encopresis). A moderately revised version of these 30 rubrics could provide a basic primary care classification which could in turn “telescope” into the full ICD or DSM classification while maintaining the integrity of these six groups. Data exchange between primary and specialty care would be greatly enhanced with this structure, as the more granular diagnoses established in specialty settings (or, where appropriate, primary care) could be correctly aggregated for use in primary care.

Primary care providers routinely identify and manage personal and social problems that do not rise to the level of diagnosable mental health disorder. Much, if not most, of this work is “hidden” due to the absence of a place in current mental health classification or coding systems for these problems. They cause significant morbidity and clearly affect outcomes of care for acute and chronic health conditions, but because they are not biomedical diseases or threshold mental health disorders, they are not labelled or counted.

A fit-for-purpose classification for primary care should include these personal and social (psychosocial) problems, not to “medicalize” them but rather to acknowledge that they exist, that they are important, and that they affect the care delivered by primary care clinicians — both directly and indirectly. Chapter Z in ICPC-2 contains 26 rubrics describing specific personal and social problems that occur relatively frequently in primary care patients, and Chapter P (psychosocial) contains several rubrics describing psychosocial symptoms (e.g. feeling depressed, feeling nervous/Ansien1). These
rubrics enable clinicians to identify and record problems that do not reach the level of a formal mental health disorder, and are of critical importance to fully describing and understanding the work of primary care clinicians. If the designers of the next-generation ICD and DSM are truly committed to improving the fit of their classification in primary care, they should find a way to enable routine recording of these problems through integration of ICPC, through adding chapters or sections to ICD or DSM, or through linkage to another dedicated classification describing personal and social problems.

6. Conclusions

Existing classification systems are unsatisfactory for primary care. Most have been adapted for, rather than developed in primary care settings; the exception is ICPC. In general, they do not capture the complexity of psychological disorder as it manifests in primary care settings, with associated physical illness and social problems. Specifically, they do not address in a satisfactory way the problems of co-morbidity, sub-threshold disorders, cross-cultural applications, or the differences between severity and impairment/disability.

A classification system for primary care should be characterized by simplicity; should address diagnosis, severity and chronicity; should be linked to disability assessment; should be simple enough to enable routine data gathering, including gathering information on outcomes; should be linked to training; and should permit efficient communication between primary and specialist care. It should also be easy to use.

This paper deals predominantly with curative aspects of primary health care services. It does not propose a classification of mental health problems for public health purposes: such a classification would undoubtedly be useful. The majority of the evidence presented in this paper comes from English-speaking sources. We recognize the limitations that this may impose, for example in relating our findings and conclusions to the situation in Eastern Europe or francophone countries. We also have not specifically addressed the issue of cross-cultural application, but consider that a simpler classification will have both greater cultural validity and application.

6.1. Recommendations

Measurement of severity of symptoms is essential in primary care settings. A solution to the problems with categorical-based systems in primary care would be to combine aspects of the categorical approach with the dimensional approach [48].

Impairment should be recognized as discrete from diagnosis or severity. A tailored mental health disability classification needs to be linked directly to the classification system. Many people with sub-threshold disorders in the current system have significant levels of disability.

We welcome the development, in ICPC, of a classification of social problems in primary care, and recommend that this classification be reviewed and revised so it can be used to support clinical data exchange between primary medical care and social care.

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<tr>
<th>“Internalizing”</th>
<th>“Psychosis”</th>
<th>“Externalizing”</th>
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<tr>
<td>Depressive disorder</td>
<td>Organic psychosis</td>
<td>Alcohol abuse</td>
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<td>Anxiety disorder</td>
<td>Schizophrenia</td>
<td>(acute and chronic)</td>
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<td>(neurasthenia)</td>
<td>Affective psychosis/</td>
<td>Drug abuse</td>
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<td>Phobia/OCD</td>
<td>BPD</td>
<td>Medication abuse</td>
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<td>PTSD</td>
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<td>(Tobacco abuse)</td>
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<td>Somatization disorder</td>
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<td>Personality disorder</td>
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<td>Feeling anxious *</td>
<td>Acute stress reaction</td>
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<td>Feeling depressed *</td>
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<td>Feeling irritable, angry</td>
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<td>Sleep disturbance *</td>
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<td>Phase of life problem</td>
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<td>Fear of mental disorder</td>
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<td>* Generalized pain</td>
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<td>Specific learning</td>
<td>Sexual desire</td>
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<td>problem</td>
<td>reduced</td>
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<td>Dementia</td>
<td>Mental retardation</td>
<td>Sexual fulfillment</td>
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<td>Organic psychosis, other</td>
<td>Psychological</td>
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<td>disorders NOS</td>
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<td>(autism)</td>
<td>Encopresis</td>
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<td>Anorexia/bulimia</td>
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Ungrouped: sexual preference concern, suicide

Fig. 1. Chapter P ICPC rubrics organized in proposed ICD-11 clusters.
Rather than reconceptualizing the categorical system of diagnosis to include sub-threshold disorders and distress, we recommend that categorical diagnoses should be more stringent and precise so that they become rarer but more significant events in primary care. This would reduce unnecessary medicalization [14] and enhance focus on those most in need of care.

6.2. Impact on help-seeking

These dimensions cover the range of information likely to be readily available or accessible during a routine primary care encounter. They build on the existing knowledge and skills of primary care health professionals, and make sense within the current parameters of primary care. They provide both doctor and patient with sufficient information to make an accurate assessment of the patients’ problems.

They also provide a strong basis for considering whether and how to intervene. Rather than relying exclusively on categorical diagnoses, the assessment of chronicity, severity, disability and social problems offers primary care clinicians (and health policy makers) crucial additional information, enabling better targeting of interventions.

This process also provides opportunity for the patient to play a substantial role. In assessment, reasons for encounter and evidence of severity and disability may be more reliably provided by the patient than the physician. This approach also offers the patient greater choice in management: whether they wish for help for their mental health problems, and if so, whether its focus should be on symptom reduction, functional ability or the resolution of social difficulties.

6.3. Training implications

It will be necessary to produce a multilingual training package in tandem with the classification system and also a specific implementation strategy aimed at diffusion within and adoption by primary care systems to a greater degree than has been the case in the past.

The collective experiences of WHO (in developing and testing ICD10-PHC) and WONCA (in developing and testing ICPC) provide a strong platform on which we can build a new classification.

References


