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APPENDIX A

CHRONIC ILLNESS AND PRIMARY CARE

(Paper commissioned by the Canadian Academy of Health Sciences in 2009 written by Barbara Starfield, MD, MPH. The views expressed herein are those of the author and do not necessarily represent the views of the Canadian Academy of Health Sciences.)

The increased burden of chronic illnesses on the functioning of health systems is well recognized. Although most of the increase in demand on the health system is a result of earlier detection of disease, lowered thresholds for making diagnoses, and, especially, increased intensity of treatment, some conditions may be increasing in frequency. Notable among these conditions are obesity and hyperlipidemia, which have moved from being considered risk factors to diagnosed chronic conditions. The increase is much greater in the US than in comparable European countries; the proportion resulting from true increases in incidence and prevalence is unknown.

Data from the early 2000s in the United States indicate that about 40% of all visits to physicians were for chronic illnesses; about 80% of these were for routine follow-up. For primary care physicians alone, 46% of visits by previously known patients were for chronic illness, and 91% of these were for routine follow-up. Although there has been a slight increase in the percentage of visits for follow-up of chronic illness, it appears that there has not been a substantial change in the percentage of visits that are for chronic illness over the past 25 years, indicating that the increase in costs is likely to be due to changes in medical practice interventions rather than to a relative increase in visits for chronic illnesses. It is also likely that the increased diagnosis of chronic illness is not a result of an increased number of people with chronic illness but, rather, an increase in multiple diseases in people with one or more already existing chronic illness. For example, the overall number of people who had one or more chronic illnesses (based on survey data) was 133 million, projected to increase to 157 million in 2020— an 18% increase. Yet the projected increase in frequency of the seven most common chronic illnesses alone is projected to increase 42%, clearly signaling a great increase in the co-occurrence of just the most common chronic illnesses. A Canadian sample of adult patients coming for appointments to family practitioners in Quebec found that over 90% had more than one chronic condition, rising from 69% in 16-44-year-old women to 95 and 99% of women of ages 45-64 and 65 and over, respectively. In men, the comparable percentages were 72%, 89% and 97%. That is, the challenge for planning and budgeting for health services is multimorbidity, not specific chronic diseases.

In the past ten years, recognition of the importance of care over time for the management of chronic illness has become widespread and, with it, the increasing importance of primary care. Heightened recognition of the high frequency of co-morbidity in people with any given chronic illness has contributed to the recognized importance of primary care, as it is that branch of medical care that deals with people’s problem en toto (“multimorbidity”) rather than the “silos” of disease and organ system oriented care provided by a multiplicity of specialists.

This paper deals with the suitability of primary care, both in concept and in practice, in dealing with the challenge of management of chronic illness, and the challenges facing it as it undertakes to deal with the increasing burden on health systems of people with multiple chronic illnesses.
The Nature of Chronic Conditions

Except for Mendelian dominant genetic conditions, which are rare in the population, diseases are professionally constructed entities. They can be and are artificially created to suit special interests. They do not exist in isolation from each other and are, therefore, not an independent representation of illness. Moreover, they are but one manifestation of ill health, among others including (but not limited to) discomfort, disability, and limitation of normal activity. A ranking of the frequency of health conditions based on lost productivity differs from a ranking based on medical costs. For example, the top five high impact diagnoses based on productivity loss are fatigue, depression, and back or neck pain, sleeping problems, and other chronic pain whereas the top high impact conditions based on health care costs are relatively infrequent cancers, back or neck pain, coronary heart disease, other chronic pain, and high cholesterol.

The system of classifying diagnoses was originally based on coroners’ reports in the early and mid 1800s and is therefore based on anatomical organ-systems. Health services system organization reflects these phenotypic classifications in its divisions of practitioners into specialty groups, which are largely based on organ systems. The increasing inadequacy of such a classification comes from a vast amount of evidence of greater variability within disease categories than across them. For example, “heart disease” encompasses 13 different rubrics in the International Classification of Diseases; to say that heart disease is the leading cause of disease provides no information about the nature of the disease, let alone the etiology or management of the disease in people and populations. Even “coronary artery disease” has diverse origins and manifestations. Chronic obstructive pulmonary disease (COPD), another leading cause of death in the world, is a syndrome with diverse systemic manifestations, not a “pulmonary” disease - although it is classified as such. Neither breast cancer, prostate cancer, nor diabetes is a single disease. The same is the case for many other “diseases” that are considered to be distinct entities with standard modes of diagnosis and intervention. Thus, lists of “priority conditions” (as in IOM, Crossing the Quality Chasm) represent the particular points of view and orientation of disease advocacy groups and disease experts, particularly specialists in those diseases. Notable “chronic conditions”, such as osteoporosis, occupational disorders and most childhood illnesses are almost never included in lists of priority diseases – a situation that under-represents the health-related needs of particular population subgroups and thus contributes to the perpetration of inequities in health in populations.

People with a diagnosis of a disease generally considered chronic (because it persists over time regardless of treatment) are, indeed, empirically found to have that diagnosis in subsequent years, thus confirming that they are “chronic”. But people with a diagnosis of an acute or acute likely to recur condition are also more likely (than people in the general population) to have the same diagnosis in a subsequent year. In analyses of clinical data, even people with conditions such as upper respiratory disease, non-bacterial pneumonia, otitis media, urinary tract infection, and headache are more likely to be diagnosed with the same condition in a subsequent year than are diagnosed in the population as a whole (Starfield, unpublished data). That is, there is no clear distinction, either on the basis of etiology or persistence, between chronic illnesses and illnesses not considered chronic.

There is a large literature indicating that experiences over the life course determine the state of health at any period during that life course. This is the case regardless of what manifestation of health (e.g., acute illnesses, chronic illnesses, disabilities) is considered. Evidence is clear that there are early antecedents of various types of illnesses as well as later influences. For example, early influences on growth and development are associated with increased rates of growth retardation, short stature, neonatal mortality, and coronary artery disease; early infections predispose to chronic respiratory conditions, rheumatic heart
disease, gastric cancer, hemorrhagic stroke, and hypertension. Later socioeconomic disadvantage predisposes to almost all conditions.\textsuperscript{19-20} In view of the evidence that the occurrence and progression of most diseases (with the exception of Mendelian dominant genetic conditions) are influenced by a myriad of interacting environmental and social conditions,\textsuperscript{21} regardless of the chronicity of their disorders, it does not make sense to concentrate attention of health services on chronic illnesses of ageing. Doing so undervalues health problems that set the stage for chronic illnesses later in life, particularly in socially disadvantaged populations. It also creates greater inequity in health between children and adults because the chronic illnesses in childhood are not the “priority conditions” targeted for health system attention. In fact, it is children who suffer disproportionately from multimorbidity. The coexistence of different illnesses is even greater in childhood than in adults although the overall prevalence of most specific illnesses is lower.\textsuperscript{22} In childhood, the coexistence of different illnesses (multimorbidity) is much greater than can be accounted for by chance distributions of illness.\textsuperscript{23}

The importance of a risk factor in a population depends on its relative risk and, more important, its frequency in the population. A relative risk of 1.5-2 with a prevalence of 90\% gives the same population risk as a relative risk of 7-8 with a prevalence of 10\% or a relative risk of 15 with a prevalence of 5\%.\textsuperscript{24} Most well-accepted risk factors have relative risks in the low range, indicating that they require a high prevalence to be salient as a population risk factor. That is why it is the combination of risk factors within individuals and vulnerable population groups that accounts for higher subsequent illness rates. That is, as with disease rates, it is the constellation of interacting risks factors that accounts for subsequent ill health, both chronic and acute. For example, prior infection (mostly sub-clinical) with cytomegalic virus raises the risk of subsequent cardiovascular disease (CVD) less than conventional risk factors, but it is so common in the population that it is associated with about 40\% of the risk of cardiovascular disease in the population (as compared with a 15-40\% for conventional cardiovascular disease risks) and for an even greater proportion of the excess cardiovascular disease in people of low SES.\textsuperscript{25}

The attribution of deaths to a single cause in tabulations of cause of death masks the importance of multidisease causation (pleiotropism).\textsuperscript{26} The sum of deaths in the world attributable to individual diseases exceeds the actual number of deaths\textsuperscript{7} and, as was noted above, the increase in the frequency of diagnosed chronic illness is much greater than the increase in the percentage of people with chronic illness.

A particular feature of all illnesses is that they increase vulnerability to other (and unrelated) illnesses. That is, existing disease is one of the myriad of interacting influences on the occurrence and progression of ill health. The extent to which this increased vulnerability is a result of underlying common pathophysiology or a direct effect of the illness on decreasing general resilience to illness, has not been quantified.\textsuperscript{27}

Despite their greater needs, people with multimorbidity are less likely to get timely treatment for particular chronic conditions. In a US study, people with uncontrolled hypertension were found to be less likely to get adequate treatment for their hypertension the more co-morbid conditions they had. The conditions with the most negative effect on odds of hypertension treatment were cancer, chronic rhinitis or sinusitis, depression or anxiety, diarrhea or constipation, emphysema or asthma, gastroesophageal reflux or gastritis, headache, nonrheumatic arthritis, and thyroiditis - thus showing how important are acute as well as chronic conditions in ongoing care.\textsuperscript{28}

Most health systems are unprepared for the onslaught of multimorbidity. The management of the large percentage of people, especially the elderly with high morbidity burdens, should be in primary care, where care is person-focused, not disease-focused. Guidelines for the management of patients with multimorbidity are needed, in order to improve effectiveness of care, to increase equity by addressing the greater health needs of socially compromised populations, and to reduce adverse events deriving from polypharmacy and
other disease-specific interventions. Table 1 provides the extent and magnitude of multimorbidity in people with particular diseases, some common and some acute. Particularly high burdens of morbidity are found in people with congestive heart failure; people with diabetes mellitus and hypertension also are very likely to have unrelated, coexisting conditions. (Johns Hopkins University, ACG Manual, unpublished; available at www.acg.jhsph.edu). There are no published guidelines for dealing with conditions in the presence of a variety of other conditions. That is, the guidelines that dominate the evaluation of quality of care are not designed to deal with quality of care delivered to most people in primary care settings. Disease-oriented guidelines face a wide variety of problems concerning their validity, applicability, and conceptual logic. They cannot guarantee a higher likelihood of either good outcomes or avoidance of harm because the evidence from which they are derived is not generalizable to the populations to which they are applied. Moreover, they are implemented on the basis of evidence of reductions in relative risk in individuals and cannot be extrapolated to reductions in attributable risk in populations. They also are likely to lead to greater inequity in health across population subgroups, as there are differences in effectiveness and safety of interventions in different population subgroups, and there is a much greater likelihood of multimorbidity in socially deprived population subgroups, and thus making disease-oriented guidelines even more inappropriate. Applicability of disease-oriented guidelines is also a concern; they assume no variability in disease manifestations, assuming that all people with a given disease are similar in responsiveness to standard interventions and are based on imperfect knowledge of the natural history of disease in individuals, subpopulations, and populations. Conceptual concerns involve their limitation to medically defined priorities for interventions. They do not address critical aspects of patient care, responsiveness to patients’ needs, or the range of services available to meet patient needs and priorities for care. Moreover, they are based on evidence that is often rife with conflicts of interest and, thus, has a high likelihood of being unethical as well as ineffective and inefficient. Importantly, they are not prioritized according to the degree to which they are likely to improve health.

Primary Care and Its Importance in Ongoing Care Over Time

Primary care is that branch of medical care that provides first-line care (by virtue of its accessibility), person (not disease) focused care over time (not just in visits), is comprehensive in that it meets all health-related needs (referring only those too uncommon to maintain competence), and coordinates care when it has to be provided elsewhere. These features make it uniquely suited to dealing with both predispositions to and manifested chronic illness.

Access to first contact care provides the basis for dealing with the approximately 10% of visits made by people with acute exacerbations of their chronic illnesses (NAMCS analyses, Starfield November 2009).

Person-focused care over time makes it possible to identify, early in life, those conditions that are likely to influence subsequent ill health and, therefore, to attempt to reduce their impact. It also provides the continuity of attention that is important in reducing the impact of chronic illnesses and reducing the likelihood of the progression to more serious illness and to more multimorbidity. In addition to its impact on increasing effectiveness of care, it is also equity producing because more socially vulnerable populations have higher multimorbidity of multiple and interacting types and thus are more able to benefit from person-focused rather than specific disease focused care.
### Table 1: Percent Distribution by Degree of Co-morbidity for Selected Disease Groups, Nonelderly Population

<table>
<thead>
<tr>
<th>Disease Group</th>
<th>CO-MORBIDITY LEVEL (RUBs)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
</tr>
<tr>
<td>Total population</td>
<td>69.0*</td>
</tr>
<tr>
<td>Asthma</td>
<td>24.0</td>
</tr>
<tr>
<td>Hypertension</td>
<td>20.7</td>
</tr>
<tr>
<td>Ischemic heart disease</td>
<td>3.9</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>2.6</td>
</tr>
<tr>
<td>Disorders of lipoid metabolism</td>
<td>17.8</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>13.9</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>11.1</td>
</tr>
<tr>
<td>Thrombophlebitis</td>
<td>12.2</td>
</tr>
<tr>
<td>Depression, anxiety, neuroses</td>
<td>8.1</td>
</tr>
</tbody>
</table>

*About 20% have no co-morbidity. Source: ACG Manual (unpublished)

Comprehensiveness of care makes it possible to deal with chronic illnesses in the context of the common situation of multimorbidity, regardless of whether co-existing conditions are simply concurrent or a consequence of the particular chronic illness. In contrast to specialist care, which focuses on one type of illness (usually organized by organ system), primary care can deal with a multiplicity of types of conditions in the context of the individual. As a result, care is more appropriate, safer, and more efficient as management is unified and less likely to involve mutually conflicting strategies. As noted above, it is also associated with greater equity of care.

Coordination provides the mechanism for interpreting and reconciling the often conflicting recommendations and prescriptions imposed by a multiplicity of disease-oriented specialists.

As a result of these features combined, primary care is associated with greater effectiveness, greater efficiency (lower costs for better outcomes), and greater equity in care. Many studies done across and within countries and using a variety of methods to characterize the strength of primary care services show that health systems and services oriented towards primary care have better health outcomes, including total mortality rates, heart disease mortality rates, infant mortality, lower low birth weight rates, and earlier detection of cancers. They also have better preventive care. (References are in Starfield et al., pages 460-66.) The stronger a country’s orientation towards primary care services, the lower the rates of all-cause mortality, all-cause premature mortality, and cause-specific premature mortality from asthma and bronchitis, emphysema and bronchitis, cardiovascular disease, and heart disease, even after controlling for a variety of other characteristics that influence health. Canada, with a moderately strong primary care infrastructure, has better health levels and better equity in care than the United States (with its weak primary care infrastructure).
Costs are also lower in systems oriented towards primary care. (References are in Starfield et al, 34 page 473.) A recent study of the impact of better primary care in Canada found many millions of dollars of savings in the care of people with diabetes or heart failure. 38

Similarly, health systems more oriented towards primary care have greater equity in the distribution of health, as has been shown for infant mortality, all-cause mortality, heart disease mortality, and cancer mortality, low birth weight ratios, and self-reported health. (References are in Starfield et al, 34 pages 469-73.) Low socioeconomic status is strongly associated with age-adjusted survival from breast cancer in the US (with a poor primary care system) but not in Canada (with its better primary care infrastructure). 39 Survival rates from various cancers showed few if any differences in the survival of various income groups in Canada but substantial differences in the United States; the survival of poor people in Canada was much better than in the US. 40

The distinction between care that is disease-focused and that which is patient-focused is at the heart of rational organization of health systems. Although it is commonly believed that the increase in frequency of occurrence of chronic illnesses over the most two decades 41 has led to a greatly increased need for and use of resources (with consequent increased costs), it is not the increase in chronic disease but, rather, the increase in multimorbidity that is the culprit. The importance of multimorbidity is highlighted by studies that show its association with increased hospitalizations for conditions that should be preventable with good primary care, adverse events rates, and, especially, costs of care. These increases are not linear; greater morbidity in terms of multiple diseases is associated with exponential rates of increase in all three, and especially in costs. 42 Analysis conducted in British Columbia used the ACG-system of characterizing multimorbidity to stratify data from a year of claims forms into people with acute conditions only, people with only low impact chronic conditions, and people with “high impact” chronic conditions, and classified people in each of these strata into the degree of co-existing morbidity burden (according to the number of different TYPES of illnesses. Within each of the nine levels of morbidity burden, people in all three groupings of types of illnesses have the same resource use. In contrast, within each of the three types of morbidity strata, resource use increased progressively with increasing burden of co-morbidity. That is, it is the degree of co-morbidity (measured by the number of different types of conditions) that influences resource use, NOT the type of condition. 43

No innovation in the management of diseases will adequately and safely address the need to prevent and manage diseases unless extent and type of multimorbidity is central in the design of the innovative intervention. Patients' health problems are neither synonymous with their diagnoses nor the sum of their individual diagnoses. Preventing and managing morbidity belongs in primary care because of its special features: first contact, person-focused care over time, comprehensiveness, and coordination. The benefits of primary care are greatest for young populations (which can benefit most from prevention of future illnesses) and for people with the highest morbidity burdens. 44-45 This is at least part of the reason why disease management programs have not proven useful, and why the promise of the “chronic care model” will not be realized in its current form. Chronic diseases and acute diseases share common etiologies; repeated acute diseases predispose to chronic diseases over the life course. A major summary of the world focus on “chronic illness management” concluded that there is no evidence of benefit from a focus of health systems or health services on chronic diseases. 46 The well known but underappreciated secret of the value of primary care is its person and population, rather than disease, focus.
Appendix A - References


35. Starfield B. Primary care and equity in health: the importance to effectiveness and equity of responsiveness to peoples' needs. Humanity and Society 2009;33:56-73.


37. Starfield B. Re-inventing Primary Care: Possible Lessons from Other Countries. Health Aff 2010 forthcoming.


