

Primary and specialty care interfaces: the imperative of disease continuity

Barbara Starfield



THE increasing complexity of the challenges of medical practice demands new modes of organising practice. Both the processes of diagnosis and of clinical management are becoming more challenging as a result of ageing (and hence more prevalent biological deterioration) of populations, increasing co-morbidity (as a result, in part, of more effective treatment and, hence, longer survival of people with more problems), increasing iatrogenesis (as a result of more invasive treatment modalities), and increasing recognition of the myriad influences on health (and, hence, of myriad alternatives for prevention and management of ill health).¹

Many countries, as well as the World Health Organisation, have recently adopted the strategy of improving primary care as a response to the challenges of improving the quality of care while minimising rapidly increasing costs. However, the burden of meeting these mounting challenges cannot be shouldered by primary care alone. Whereas health services in general have been responsible for a substantial proportion of the increase in life expectancy in the last half century,² at least one-third of this is solely attributable to primary care (Bunker *et al*, unpublished data, 2003). The additional degree to which primary care (particularly in an increasingly specialised medical environment) has contributed, through its referral patterns, to the overall positive effect of health services is unclear. How much are the benefits of health services

Barbara Starfield, MD, MPH, FRCGP, university distinguished professor, Johns Hopkins School of Public Health, Baltimore, USA. This text is based on the William Pickles Lecture, which was delivered at the Spring Symposium of the Royal College of General Practitioners at the University of Bristol, on 6 April, 2003.

Address for correspondence

Professor B Starfield, Johns Hopkins School of Public Health, 624 North Broadway, Room 452, Baltimore, MD 21205, USA. E-mail: bstarfie@jhsph.edu

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attributable to the relationship between primary care and specialty care?

There is little information that addresses this question or, even, that considers the way in which the relationship should be envisaged. Little attention (at least in Anglophone countries) has been devoted to developing either consensus-based or evidence-based guidelines for referral from primary care to specialty care and, in fact, the need for evidence on relative degrees of benefit does not appear to have been recognised.

This paper provides a general framework for starting a process of rationalisation, and some preliminary evidence that could inform strategies to proceeding further. The data come primarily from national samples in the United States (US) — the better organisation of general practice in the United Kingdom (UK) may be associated with far better communication between primary care physicians and other specialists in the UK. Nevertheless, the data presented herein raise questions that are more generally applicable in all countries, and the US data provide a basis for cross-country comparisons.

A different look at morbidity

The case for a better primary care orientation or, at least, for better continuity of care in health systems, is generally justified by the increasing burden of chronic illness in populations. In fact, the case is more compellingly made on the basis of co-morbidity of illness, whether acute or chronic. There is little doubt that illnesses are not randomly distributed in populations but, rather, that they cluster in particular individuals and in population subgroups. Concepts borrowed from genetics are more generally relevant; aetiological heterogeneity (one disease can have a range of 'aetiologies'), penetrance (the likelihood that illness might not be manifested even in the presence of the presumed 'cause'), and pleiotropism (the existence of different illnesses, given a particular 'cause') apply more generally to illness in populations. The reason for this is that the nature of 'causation' (or more appropriately, 'influences') is multifactorial (except for rare Mendelian disorders), both in individuals and in populations.³ The different influences potentiate and modify each other, leading to the likelihood not only of additive effects but also multiplicative effects, thus explaining the 'clustering' of illness.

Co-morbidity is the norm in people with an illness. That is, more people have multiple diagnoses than can be accounted for by random distribution of illness in the population.⁴ Although there is increasing morbidity with increasing age, the extent of co-morbidity in the youngest age groups (children) is much greater than expected by chance distribution than is the case in older people.⁴ Co-morbidity is a burden on the health services system as well

as on the individual or sub-population. Co-morbidity has a major impact on hospitalisation and on the rate of occurrence of adverse effects. In 1999, for example, 65% of the US elderly (aged 65 years or older) had two or more types (generally categorised by an organ system involvement or aetiology) of chronic conditions. Inpatient admissions for ambulatory care-sensitive conditions (conditions for which hospitalisation should be avoidable with good primary care), and hospitalisations for preventable complications increase much more than linearly with each additional co-morbid condition. Those with four or more types of conditions were 99 times more likely than those without any chronic conditions to have an admission for an ambulatory care-sensitive condition. Per capita expenditure increased similarly, from US\$ 211 for individuals without a chronic condition to US\$ 13 973 for those with four or more types.⁵

The current focus on the importance of chronic illnesses in contrast to acute ones may be exaggerated. Having a diagnosis in a particular year, even a non-chronic one, increases the likelihood of having it in subsequent years, even years later. For example, individuals who have an upper respiratory tract infection are 60% more likely to have a diagnosis 2–3 years later than individuals who do not have that diagnosis in a particular year. The increased likelihood of recurrence rises to twice as likely for pneumonia, 2.3 times as likely for sinusitis, almost three times as likely for abdominal pain, over three times as likely for otitis media, four times as likely for urinary tract infection, and four and a half times as likely for headache. On the contrary, even frankly chronic conditions are not uniformly 'present' (diagnosed) in subsequent years, even 2–3 years later. For example, the diagnosis of auto-immune disorder in subsequent years is 641 per thousand people who had it in one previous year (B Starfield, Unpublished data, 1996–1997). Admittedly, part of this may be a result of the tendency of 'rule-out' diagnoses to be coded as the diagnosis itself in many data systems.

The clustering of unrelated diagnoses (co-morbidity), its impact on costs, hospitalisations, outcomes, and continuity of morbidity (persistence or recurrence over time) suggests the utility of new types of interfaces between primary care and specialty care. A major challenge, however, is that we know very little about the utility of current interfaces, or about the nature of special care and the contribution it makes to dealing with the continuity of morbidity.

We do, however, know a few things. For example, primary care physicians have professional relationships with a very large number of specialists. Robert Reid and colleagues, using data from British Columbia, Canada, have shown what the distribution of this phenomenon is. The modal number is 100–124; the distribution tails off but not until over 400 is reached! We still understand very little about the nature of these relationships and why their frequency should vary so much (Reid R, *et al*, unpublished data, 2003).

Referrals from primary care to specialty care

A recent comparison between the US and the UK in the percentage of people referred from primary care to at least one

specialist in a year showed a large difference, such that the percentage was about three times higher in the US than in the UK, even after control for degree of morbidity burden, age and sex.⁶ The actual differences may even be underestimated, as the US data are drawn from managed-care organisations that attempt to reduce the occurrence of referrals. The findings are consistent with earlier findings from the European referral study,⁷ which showed the variability in referral percentage in 15 European countries and provided detail on the percentage that were for medical, surgical and other reasons. (The variability was even greater to specialists in obstetrics and gynaecology, psychiatry, emergency medicine and oncology). It is also of interest that referral rates vary indirectly with the frequency of the problem encountered in primary care as well as directly with the degree of co-morbidity (as noted above). More uncommon problems are more frequently referred at each level of co-morbidity.⁸

The importance of adjusting for morbidity burden was shown previously in a study of referrals in a large Health Maintenance Organisation. Variability in referral rates among physicians was greatly reduced when their patient populations were adjusted for differences in case mix, characterised by the Johns Hopkins ACG system of diagnosed morbidity burden.⁹

Various studies in the US have shown that practice-based approaches to restricting access to specialists have little effect on referral rates;^{10,11} key determinants appear to be the frequency of the problem as encountered in primary care, case mix (with higher degrees of co-morbidity related to higher rates of referral), and policies in specific health-care systems; for example, the UK versus the US.⁶ In The Netherlands, where the 70% of individuals with public health insurance require a referral each time they see a specialist, overall rates of specialty visits are lower than is the case for the 30% of people with private insurance, who have more flexibility in their ability to visit specialists without repeated referrals.¹²

Who needs to see specialists?

Seeing a specialist is not a random affair, nor is it associated with differences in the frequency of illness in different populations. For example, rates of visiting specialists are directly associated with social class: the higher the social class, the greater the rates of seeing specialists even in countries where rates of seeing generalists are inversely related to social class, and even though rates of illness (and especially severe illness) are inversely related to social class.^{12–16} The extent to which this is a result of differences in referral rates or differences in self-referrals to specialists is unknown.

In some countries (such as the US), about half of the total number of office-based visits involve specialists.¹⁷ However, when viewed from the perspective of people rather than visits, the number of visits to primary care physicians in a year for almost all specific conditions exceeds the number of visits to specialists for these conditions, both for specific common conditions as well as for co-morbid conditions in the same people. This pattern is found across almost all conditions in the non-elderly population.¹⁸ (The exception is for

some uncommon conditions, such as diabetes mellitus in children, for which the number of visits to specialists for diabetes exceeds the number of visits to generalists, but only for the diabetes.¹⁸⁾

Figure 1 provides an example for adults with asthma. The number of visits to generalists for co-morbidity is greater than the number of visits for the selected condition; also, the number of visits to generalists for co-morbidity is greater than the number of visits for co-morbidity to specialists. That is, primary care providers are the major providers of care *both* for particular chronic conditions as well as other conditions, for all degrees of co-morbidity, except in the case of a few unusual chronic conditions, where specialists tend to provide the majority of care for the conditions themselves.¹⁸ It is also true that the greater the co-morbidity, the relatively greater the number of visits to specialists.

Even when viewed from the episode perspective, specialists are involved in only a minority of cases; cardiologists in 36% of those with cardiac disease, orthopaedic specialists in 22% of those with musculo-skeletal conditions, and neurologists in 40% of those with nervous system disease (M Spitzer, personal communication, 2001). Although all of these data derive from patients in managed-care plans, and hence probably underestimate the percentage of people who consult specialists, they undoubtedly overstate the amount of specialist use in healthcare systems where referral rates are lower and where patients either may not or do not go to specialists without a referral from primary care.

Thus, with the possible exception of long-term management of very uncommon conditions, specialists appear to play a lesser role in the care of patients (although not necessarily diseases) than do primary care physicians, at least in the non-elderly.

Roles of primary care and specialty care

Primary care plays a well-defined role within health services systems. It is first-contact care, person-focused over time, comprehensive, and coordinating. First-contact care means that it is the locus of care for all new or newly recurring problems or needs for care in the population. Person-focused care over time means that it is devoted to care of individuals in a population. It deals with the constellation of diseases or disease states (co-morbidity) rather than focusing on specific diseases. Comprehensiveness includes caring for all health-related problems in the population except for those that are too uncommon for competence to be maintained. It coordinates care for those in the population who require services outside of primary care.

The role of specialists is not so well understood. Among the functions are short-term advice or definitive interventions for which primary care physicians do not have the equipment, skills or experience needed to perform them. It may also be continuing long-term care when primary care physicians need ongoing advice in the management of certain problems in particular patients, or it may involve transferred management when the problem is too uncommon to be managed by primary care practitioners. Another level of specialty care is for short-term, highly-skilled inter-

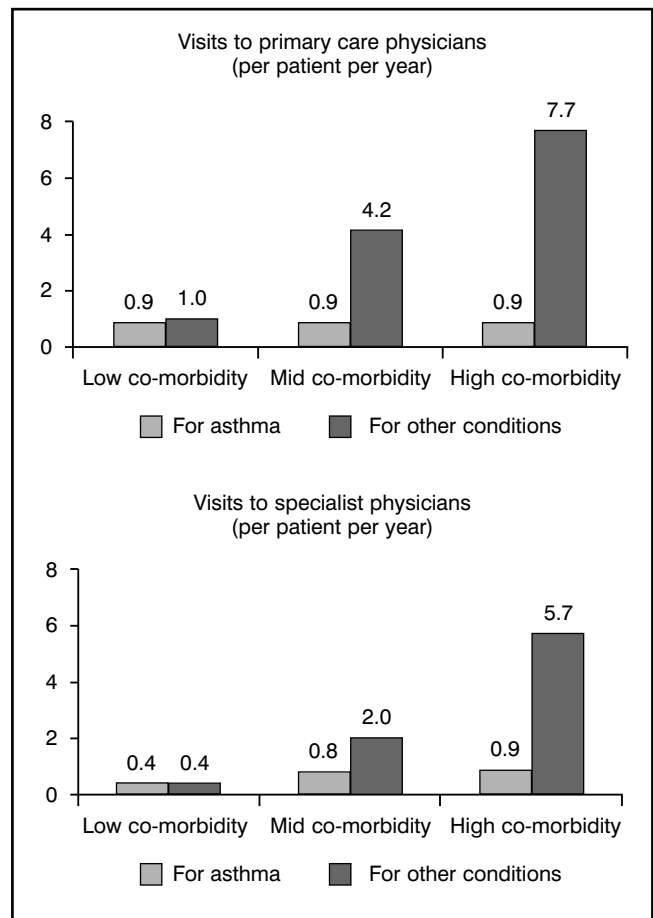


Figure 1. Adults with asthma.

ventions usually carried out in high-level medical institutions, such as teaching hospitals.

Figure 2 depicts the complexity of referrals. In some places, patients may go directly to specialists without a referral from primary care and without financial penalty. This is the case, for example, in the US, Germany, Belgium, France and Japan and, for particular specialties, in Denmark and Spain, and in Finland according to insurance type. Where referrals emanate from primary care, the basis for the referral may be simply the reason for encounter, a need for help or confirmation of a diagnosis, a need for help with management decisions or short-term management itself, or a need for ongoing management; it may also result from a specialist's decision that a referral from another specialist is required for any of these reasons. Sometimes, referrals may result for a multiplicity of these reasons.

In the case of referral for definitive treatment, the need may be for the short term only, or it may be for the long term; if the latter, the primary care physician may anticipate sharing the responsibility for the patient or, alternatively, may transfer all management (at least for the particular problem generating the referral) for ongoing management.

Reasons for referral — empirical observations

In the US, at least, most referrals (48%) from family practitioners are for advice on treatment, followed by advice on

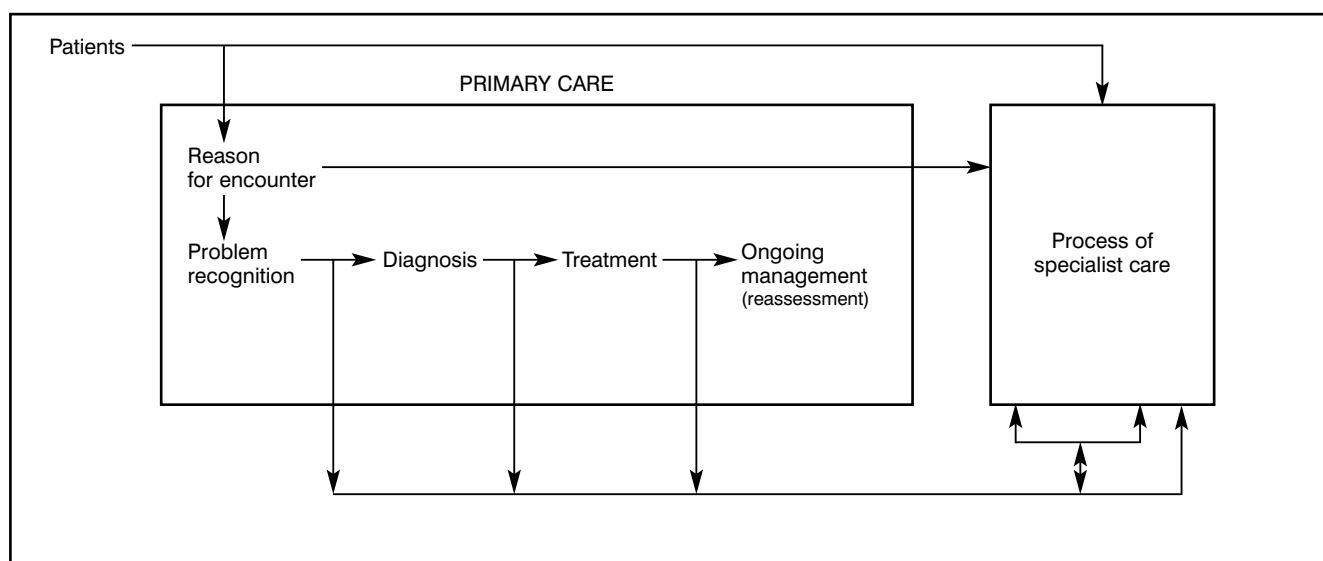


Figure 2. Referral from primary care.

diagnosis (44%). The same is the case (about 62% and 47%, respectively), for treatment advice and diagnosis advice for referrals from office-based paediatricians (most of whom are primary care practitioners for children in the US). Definitive management provides the basis for referral in about 40% of referrals from family practice, and about 30% in paediatrics. Patient requests are present in 16% of referrals from paediatricians, followed by failed treatment, mental health counselling, and multidisciplinary care.¹⁹⁻²⁰ For family physicians, these combined reasons are present in about a third of referrals. In this sample of family practitioners and paediatricians participating in collaborative practice-based research, about half of all referrals were to surgical specialists, and the expected duration for completion of the referral was less than three months for 60% of the family practice referrals and 40% for those from paediatricians.¹⁹⁻²⁰

Considerably more referrals are for consultation than for transfer of responsibility, even in the short term. The percentages for consultation in family practice and paediatrics are 56% and 40%, respectively. Referrals where shared responsibility is anticipated are 29% and 35%, respectively, and for referral with transferred management, they are 15% and 25%, respectively.¹⁹⁻²⁰

The types of referral by family practitioners vary according to the specialist to which the patient is referred. For 11 out of 15 specialist types, more than 50% are for short-term consultation. Short-term referrals for definitive diagnosis or management account for 25–30% of referrals to dermatologists, neurologists, respiratory specialists, otolaryngologists, orthopaedic surgeons, psychologists, psychiatrists, and non-physician practitioners.²¹

Expectations for referral also vary by the type of specialist.²¹ In family practice, consultations for advice account for about a third of referrals to neurologists and about 25% to psychiatrists. Consultations for tests and procedures account for at least 30% of referrals to all specialists except psychologists and psychiatrists, and are particularly high in the case of general surgeons, urologists, and obstetric and gynaecology specialists.

More than a quarter of family physician referrals are expected to be associated with shared management for referrals to all specialties except general surgery, urology, and obstetrics or gynaecology; referrals with transferred management occur in fewer than a quarter of referrals to every specialist type. In paediatric practice, short-term consultations account for more than 50% of referrals to cardiologists, allergists and gastroenterologists. For general surgeons, ophthalmologists, urologists and dermatologists, more than 25% of referrals from paediatricians are for transferred management. For the remainder of the specialist referrals, more than 25% are for shared management — a finding similar to referrals in family medicine, where the predominant expectation in at least six of the specialty types is referral with shared management.²¹

Coordination of care between primary care and specialist physicians

If the frequency of referrals from primary care is as high as 15% to 30% of people in a year, coordination of care is an important consideration. For this reason, coordination (or integration) of care is one of the key features of primary care practice.²²

Efforts in coordination by the primary care physician are greater in family practice than in paediatric practice, at least in the US. More than two-thirds of family physicians actually scheduled the specialist visit, more than four out of five sent pertinent information, and fewer than one in ten had no communication. In contrast, fewer than four in ten paediatric referrals were associated with making the appointment and sending information; in about four out of ten there was no communication reported by the paediatrician.

Communication about the result of the referral was relatively high in both family practice and paediatrics. The referring physician was aware that the visit was made in 43% of referrals from family practice and 65% of paediatric practice; feedback about the results of the referral (when the visit was made) was received in 81% of family practice referrals and 55% of paediatric referrals, and this feedback

consisted of a letter from the specialist in 77% of family practice and 44% of paediatric referrals (Forrest *et al*, unpublished data, 2003).²⁰ UK doctors might react with surprise at these apparently low figures. However, it is not clear that they are any higher in the UK, and existing referral studies do not appear to have addressed the issue.

There was a strong relationship between communication at the time of the referrals and communication post-referral, at least in paediatric primary care practice. The odds ratio for getting some feedback about referrals from paediatrics was 3 when the referring physician scheduled the appointment and sent information, 1.8 when the appointment was scheduled but no information was sent, and 1.5 when information was sent but the appointment was not made by the referring physician.²³

Greater benefit from the referral was achieved when coordination was better (Table 1). When both a letter was received and there was telephone feedback, all three measures of benefit (satisfaction of the primary care physician, perceived benefit to patient management by the primary care physician, and perceived educational benefit to the primary care physician) were ranked the highest. When there was neither a letter nor telephone contact, the ratings of all four were lowest, with intermediate values when there was either a telephone conversation or a letter.²³

Implications for relationships between primary care and specialty practice

The findings of the reported studies make it clear that primary care practitioners are central to the care of people with all illnesses, whether this is because the illnesses themselves are common and therefore in the purview of primary care, and because of the high tendency of all illnesses (including acute ones) to persist or recur, or because of the large extent of co-morbidity within the population, especially within subgroups, including the socially disadvantaged and those with more uncommon illnesses.²⁴

Therefore, new roles for primary care physicians and other specialists are in order. One alternative is to allow or encourage family physicians to sub-specialise in certain aspects of primary care (as is being done in the UK), but there is continuing concern that such specialisation will undermine the more important role of generalist primary care. In the case of common conditions (perhaps more than two per thousand in a practice population), there is strong imperative, when the disease is likely to be serious and persist or recur over time, for a shared mode of relationship between primary care physicians and specialists. In these instances, more thought might be devoted to considering the role of the specialist as a consultant to the

primary care physician rather than referring the patient to the specialist when there is no need for a definitive intervention, i.e. for diagnostic tests or specific therapeutic procedures in which primary care physicians have no expertise. There may even be justification for training primary care physicians to carry out diagnostic and therapeutic procedures now in the province of specialists, when the need for these is common and primary care physicians could therefore maintain competence in dealing with them. This seems particularly promising in the case of common dermatological conditions as well as minor surgery, which, in the US at least, are often referred to specialists. In fact, in some places, specialists visit primary care practices on a periodic basis to see groups of patients with the same common condition, although the frequency and nature of such approaches is poorly documented and not well evaluated. This system has the advantage of greater convenience for patients, as well as being of educational value both to primary care physicians and to specialists, who learn better what common diseases look like when they appear in the community rather than in the relatively isolated world of specialist practice. It is also likely to make specialists more aware of co-morbidity in patients with conditions in their sphere of special competence and could greatly inform the development of guidelines for evidence-based medicine, most of which have been developed from trials in patients without co-morbidity. Co-morbidity is common.¹⁸ It also has a major impact on need for care. On the grounds of effectiveness and efficiency, guidelines need to be relevant to people with co-morbidity as well as to those without it.

A recent report from the UK of a randomised controlled trial of joint telecommunications²⁵ indicated a reduction in the number of tests and procedures in the group of patients 'seen' jointly by the primary care practitioners and a specialist. Although more patients in this group were offered the opportunity of a subsequent specialist consultation, there was no increase either in the number of subsequent specialty contacts or the number of primary care contacts. In addition, patients expressed greater satisfaction with care and a health status that was no worse than in the group referred initially by the primary care physician to a specialist.

A previous report from the UK of an evaluation of the increasing number of specialist outreach clinics (conducted in primary care physician offices approximately every four weeks) showed that patients spent less time on waiting lists for specialist appointments, had shorter waiting times in clinics, and fewer follow-up appointments, and that they were more likely to be discharged than patients

Table 1. Referring physician benefit from referral to selected US paediatricians, mid-1990s.

Feedback	Satisfaction ^a	Benefit to management	Educational benefit
Letter and telephone	1	1	1
Letter only	2	3	3
Phone only	3	2	2
None	4	4	4

Source: ²² Forrest *et al*. ^a with 1 denoting the highest level of satisfaction, and 4 the lowest

seen in hospital outpatient clinics, although total costs to the health system were greater.²⁶

The issue of equity in health services, based on differences in equity of health needs, bears recognition and study. The several studies that have explored the nature of care across the socioeconomic spectrum indicate clearly that, while some health systems have succeeded in equalising the use of primary care services (with some even achieving the goal of more services in populations with greater needs), there still remains a gap in receipt of specialty services by socially deprived groups.¹²⁻¹⁶ On the grounds of equity alone, the relationship between primary care and specialty services demands more attention.

An unresolved issue is the benefit of referral to specialists. Although evidence is sparse, it is consistent in suggesting that population health (as distinguished from processes of care for specific disease) is worse when specialty to population ratios are high²⁷⁻²⁸ or when use of specialty services is highest.²⁹ However, it is possible that certain aspects of specialist care (such as disease-oriented prevention) may be enhanced by the appropriate use of specialty services.¹⁶

It appears essential that health policy deliberations increasingly pay attention to the appropriate balance between primary care and specialty services. It appears self-evident that the diagnosis and management of rare conditions, or rare manifestations of common conditions, are in the province of specialists, as primary care physicians will not see enough of these to maintain competence in dealing with them. Preliminary data suggest that perhaps 1-2 per 1000 population may be an appropriate threshold for rarity, but this estimate is not based on any firm evidence. Moreover, it may be that at least some proportion of these could be managed in primary care, once diagnosis and initial therapy are instituted, with adequate consultation from specialists. The vast majority of the need for specialty care will occur, however, in the case of common conditions, when there is a need for specialised services (diagnostic or therapeutic) in the short term. Preliminary estimates are that 12-15% of people may need such services in a year. As the data presented herein indicate that some countries (eg the US) have far higher use of specialty services, the issue of over-utilisation of specialty services becomes relevant for policy consideration. Attempts to reduce unnecessary use of specialists in the US have not proven to reduce the use of specialists, either because of uninformed public opinion about the value of specialty care where it is not needed or because of fears of malpractice regarding under-treatment among physicians.

Nevertheless, there is a point at which the unnecessary seeking of care from specialists becomes dangerous to health. When the actual prevalence of a problem is low, diagnostic interventions have high false-positive rates, leading to additional diagnostic and therapeutic interventions that have unintended adverse effects on morbidity and unnecessary deaths. Referrals for common and relatively undifferentiated problems will lead to unnecessary and dangerous interventions when the intent is to rule out an uncommon condition. It may be hypothesised that

more advantaged populations are more susceptible to such effects because of their easier access to specialty services. Conversely, socially disadvantaged populations are likely to be compromised because of their lower rates of use of specialists for appropriate diagnostic and therapeutic interventions for both uncommon as well as common conditions. Populations deprived of adequate financial means suffer declines in both appropriate as well as inappropriate services.³⁰

Thus, referral policy is critical both with regard to the effectiveness of services as well as to the equity of their distribution. With increasing worldwide interest in both of these issues, greater attention to the relationship between primary care and specialty services is warranted.

Conclusion

Morbidity is a continuing process in most people — a result of genetics interacting with environment in very complex ways, involving a large number of interactions at the molecular level as well as between the social, physical, material and psychological characteristics of the individual, the community and policy.

As a result, person- and population-focused health care requires continuity, both within primary care as well as across different levels of care. This paper shows what little is known about the nature of the interface between primary care physicians and specialist physicians. The imperative now is to assess the generalisability of the findings, develop a framework (or adopt the suggested one) for guiding new policies, and make changes based on evidence of effectiveness, efficiency and equity.

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