

Timothy J. Steiner

Health-care systems for headache: patching the seam between primary and specialist care

T.J. Steiner (✉)
Division of Neuroscience, Imperial College
London,
Charing Cross Campus, St. Dunstan's Road,
London W6 8RP, UK
e-mail: t.steiner@ic.ac.uk
Tel.: +44-20-8846-1191
Fax: +44-20-8741-7808

Abstract Health services are rarely highly successful in meeting the needs of people with headache disorders, who everywhere are low in the priority queue. Taking the UK as an example within Europe, this paper briefly reviews the present organisation of headache services, and proposes change. The solution does not appear to lie in expanding specialist headache centres in secondary care to which most people with needs fail to gain access. A three-tier system with emphasis on primary care will, it is argued, deliv-

er care more cost-effectively and more responsively to patients' needs.

Key words Evaluation • Headache • Health care • Needs assessment • Primary care • Secondary care

Introduction

In the World Health Organization's (WHO) Alma-Ata declaration [1], primary health care is "the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work". The United Kingdom (UK) has a strong system of primary care [2]. It is historically a pillar of a Beveridgian national health service (NHS) which has statutory responsibility for providing comprehensive health care, paid for out of general taxation and essentially free at the point of delivery.

Models of health care vary elsewhere in Europe, some supported by insurance-based financial structures operated by the State or in which the State acts as a controlling intermediary. But, in nearly all countries, primary care has a recognised and important role. Decisions in primary care take account of patient-related factors such as family med-

ical history and patients' individual expectations and values of which the continuity and long-term relationships of primary care generate awareness. Continuity of care engenders trust and satisfaction amongst patients [3].

In the UK NHS, general practitioners (GPs) in primary care have always had a gate-keeper role, controlling access to specialists in secondary care [4, 5]. This is not the case in all European countries; in France and Germany, for example, patients may go directly to a specialist, who therefore becomes the first contact. By its nature, specialist care is usually provided in a hospital environment that has the complex technological facilities necessary to perform clinical investigations, surgery and post-operative care.

Gate-keeping ostensibly guides patients efficiently and in their best interests through the system according to their needs rather than their demands. However, whatever its supposed purpose, gate-keeping by GPs in the UK is believed to have contributed to maintaining low levels of expenditure on the NHS in comparison with health-care systems else-

where. Today the gate-keeping role of primary care is regarded as essential for cost containment, in part because of evidence that unrestricted access to specialists induces a demand for costly and sometimes unnecessary services. The effectiveness of this system [6], and the equity of it, rely to a great extent on what happens at the *interface* between primary and secondary care, a seam in service continuity where breakdowns generate a state described as “limbo” in which patients feel that progress towards recovery ceases [7].

There is clear evidence that countries undertaking health-care reform are shifting away from secondary care towards primary care [8]. The UK exemplifies this in its politically driven reorganisation of and diversion of resources within the NHS beginning in 1990 [9] and becoming more explicit in 2000 [10]. The *NHS Plan* envisaged significant expansion in numbers of GPs, who would work cooperatively, grouped geographically within Primary Care Trusts (PCTs) responsible not only for primary care but also for managing many community health services and for commissioning services from secondary-care providers such as acute care hospitals [10].

Headache services now in the United Kingdom

The WHO recognises headache disorders as a high-priority public health concern [11] in a world-wide context of significant need arising from headache disorders but low priority given to them in the queue for health care [12]. Headache disorders are common [13–18], in many cases lifelong conditions and associated with recognisable burdens that include personal suffering, disability and impaired quality of life [19–23]. Their impact extends beyond those immediately affected [24].

Consequently, large numbers of people with headache are seen by GPs – and by neurologists [25, 26]. Of a sample of patients aged 16–65 years registered in a large general practice, 17% consulted because of headache at least once in 5 years [27]. Despite this, care is not reaching all who may benefit. Only 67% of adults in this age range with migraine are correctly diagnosed [28]. Whilst 86% consult at some time, many lapse from care so that only 49% are currently consulting; over 60% of those not consulting nonetheless exhibit high migraine-related disability [28]. The same undoubtedly goes for other headache disorders. Data from the same general practice show that 9% of those consulting for headache were referred to secondary care [27]. Neurologists receive by far the most of these referrals: up to one-third of all patients consulting neurologists in the UK do so because of headache, more than for any other neurological condition, and numbers are increasing [29]. As each neurologist in the UK serves an average of 175 000 people, the

median waiting time to be seen is 28 weeks – a perfect example of service-continuity breakdown at the seam between primary and secondary care [7].

The large numbers of headache referrals to neurologists are impossible to justify: only a small minority of cases of primary headache are *not* best managed in primary care with skills expected to be generally available [30].

Proposals for change

Opportunity for change – doing things differently and better, establishing the right structure for headache services with the optimum involvement of primary care – arises now. It does so because of the government’s commitment described above to a new “primary-care-led NHS” [10] which takes emphasis, and potentially money, away from the acute care hospital sector and moves them to a more broadly defined primary care [31]. The expected result is the appearance of different models of integrated care, shared care schemes, specialist outreach services and other forms of substitution for hospital care. GP-specialists – primary-care physicians with special expertise in specific therapeutic areas, able to provide more complete care for patients outside hospital [32] – are one anticipated and important consequence [33].

It was in this context that the British Association for the Study of Headache (BASH), following a national consultation process, made draft recommendations for change [30]. The essential elements are that the role of primary care in the management of headache disorders should be expanded, with headache services reorganised on three levels. General practitioners, with better education, should provide front-line headache services for their patients (*level one*). Within each PCT, one or more primary-care headache centres (PCHCs) should be established (*level two*), staffed by GP-specialists, to which local GPs at level one might refer those patients requiring more skilled care. Hospital-based specialists (*level three*) should provide necessary support to level two, and facilitated access for the relatively few patients from levels one and two needing secondary-care management.

The expectations of level two embrace improved headache services, achieved by patching the seam at the primary-secondary care interface. In particular, level two is charged with: (1) extending community-based headache services and making them effective in meeting need; (2) cutting costs by reducing waste and improving efficiency of service delivery by pulling inappropriate headache referrals to secondary care back into primary care; and (3) thereby freeing resources to discover and meet unrecognised headache-related health-care needs in the community.

Will the proposals work?

Change should be evidence-based, but evaluation is a major problem. The proposals are not readily amenable to a controlled intervention study such as comparing one area with a PCHC and another without, or randomising at practice/GP/patient level within one area so that one group of the population is offered the service and another group is not. Concerns about the equity of this approach may relate mainly to perception, whilst there are genuine ethical difficulties in seeking to make comparisons between groups of patients where those in one become a control group without the opportunity to consent to being observed. Furthermore, existence of the service, and observation, are both likely to change practice even where the service is not directly available (Hawthorne effect).

Indent Evaluation, in part qualitative, is necessary in at least six domains: practical or technical success (do the proposals work?); uptake (is the service used?); clinical effectiveness (has the service improved?); patient satisfaction (do patients agree?); success in tackling inequality (is the service equitable?); and cost-effectiveness (is the service affordable?). I shall consider further only four of these.

Clinical effectiveness

Standard outcome measures exist for some headache disorders for use in clinical trials, but they have recognised limitations. In the case of service development it is not sufficient to assess outcomes only in those with known headache: this will not measure success or failure in identifying and diagnosing those not complaining of or not already receiving treatment for headache (unrecognised need), who are likely to be numerous and in whom burden may nevertheless be significant [28]. Evaluation must measure *population* headache burden over time, before and during intervention. BASH [34] suggested an adaptation of MIDAS [35] for this purpose.

There are problems, though. Population-based measures are relatively insensitive. Additionally, all methods of longitudinal evaluation assume a certain stability of the local population which may not prevail: in some areas of London, for example, annual turnover of the population is up to 30%.

Patient satisfaction

Patients are rightly the arbiters of whether change to service delivery constitutes improvement. The UK charity, Migraine

Action Association, advises that headache patients have clearly expressed views on what aspects of a headache service are highly important: timely access to services nearby, in primary care rather than hospital-based; interested staff who take them seriously; sufficient information and explanation; follow-up when needed.

Interestingly, these all relate to *process* rather than *outcome*. Patients believe that if the process is good, so will be the result. Whilst these requirements can be (and are) built into proposals for change, it is unclear what benchmarks may be appropriate against which to judge achievement.

Tackling inequality

There is evidence that the more socially deprived experience greater difficulty in accessing health-care services and obtain less good care with poorer outcomes [36]. Improving access does not guarantee benefit to the sub-groups of the population who most need to be reached [37]. Factors expected to affect access (e.g. patient characteristics such as socio-economic status and ethnicity) can be monitored in order to be aware of special problems that may apply to certain groups, but there are likely to be others that are not readily apparent.

Cost-effectiveness

Service development requires either the investment of further resources or improved efficiency in applying those currently allocated. Neurologists are scarce and relatively costly. Primary care has generally lower overheads, so GPs may be less resource-consuming, but they are in no position to add to their own work loads. More GPs will be needed if headache services are relocated to primary care. Almost inevitably, if services are improved or merely moved to where patients are, more patients will seek care. Demand will rise, as will costs if any of this new demand is met. If further resources are required, the associated opportunity cost (the alternative uses to which those resources might otherwise be put) must be duly considered.

At least for this there is established if not wholly comprehensive methodology. Cost evaluation can measure direct treatment costs – the overall and per capita costs of providing care (i.e. the costs to the health-care system): primary-care consultations at levels one and two, use of investigations including computed tomography (CT), referrals to secondary care and prescriptions. Some of the added costs of enhancing headache services in primary care will be offset by savings both within this setting and elsewhere: e.g.

costs should be recovered to primary-care budgets by cut-backs on wastage through mismanagement including prescriptions of inappropriate medication, and to commissioning budgets through avoided referrals to secondary care. Where neurologists' work loads are reduced, analysis must include how they utilise released time (opportunity gain). Paradoxically, benefits accruing from shifting headache services to primary care may be seen in better secondary-care management of epilepsy, multiple sclerosis and Parkinson's disease.

An important issue is that assessable costs are not limited to direct health-care costs but widened to include the much larger non-health-care costs, where savings are more likely to accrue. As an example, an estimated 25 million working days per year are lost in the UK to migraine alone [18]; some at least of these may be recovered.

Conclusions

There are many problems with the current compartmentalised division of headache services between primary and secondary care. In the UK, and wherever health-service reform is shifting resources from secondary to primary care, there is opportunity for change. Beneficial change requires *education* at a number of levels: these problems, and the priority that should be accorded to headache services, must be acknowledged if change is to be made to happen.

Distorted priorities may be at the heart of the current inadequacies. Some albeit imperfect data allow comparison, on the basis of NHS spending, between health-care provi-

sions for headache and for another condition causing widespread pain and disability in the population: low back pain. Like headache, back pain is a leading cause of sickness absence from work. An estimated 11 million working days were lost in 1995 from musculoskeletal disorders including back pain [38]. As noted above, amongst headache disorders, migraine alone is estimated to account for more than double this [18]. Against this background of relative societal costs, direct NHS costs of migraine in 1991 were estimated at £23–30 million for all of the UK [39, 40]. Whilst these are the most recent published calculations, with the advent since then of new and relatively expensive drugs, costs today are certainly higher. It is reasonable to assume that changes in consultation rates and requests for investigations are relatively small (certainly less than 2-fold) whilst drug costs, principally for triptans, can be re-estimated on published data [41] at some £60 million per annum. Whilst there is some uncertainty about this estimate, and the overall total of perhaps £100 million, the most recent calculation of annual NHS expenditure on back pain was very much higher at £481 million [38].

Therefore, whilst major improvement to services requires significant investment, there are opportunities for substantial savings to offset it. A GP-specialist service bridging the seam between primary and secondary care may provide solutions to (some) current failures, but measuring the benefits of change is a challenge.

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