interpreting the results of ‘genetic’ data where there is little information on segregation, unestimated heterogeneity, uncertain clinical context and no functional information. Reproducible identification of mutations in well-characterized populations and compelling functional data will be required to strengthen the case for a specific gene. ‘Private’ mutations in single families with atypical phenotypes will be difficult to confirm and will remain of uncertain relevance.

The genes identified in human diseases can now be evaluated in highly tractable model systems, such as the mouse and the zebrafish, helping to confirm these genes as disease-causing and to dissect the pathways from mutation to phenotype. Genome-wide analyses of these pathways offer rigorous methods for identifying true candidate genes that can then be tested in human populations. This two-way interchange between human disease and model systems will eventually fulfil a major goal of genomic approaches in heart failure; the identification of all the genes important in dilated cardiomyopathy.

C. A. MACRAE
Massachusetts General Hospital, and Harvard Medical School, Boston, Massachusetts, U.S.A.

References


Parallel realities of guidelines and practice

See page 1877 for the article to which this Editorial refers

There are at least three good reasons for reading the paper by Hobbs et al.[11] in this issue:

(a) it is focused on an area of care which is increasingly important in cardiology and public health;
(b) it recalls and underlines one of the most neglected aspects of heart failure, namely the conditions of discontinuity between specialist and general care;
(c) it is an attempt to provide a comparative view of the cultural attitudes and perceptions in different medical settings and health care systems.

There are at least three directly opposing reasons to suggest that the results should be taken as a stimulus for looking ahead, more than as a set of hard information on which to concentrate technical, or policy, discussion:

© 2000 The European Society of Cardiology
(a) despite validation processes, questionnaires remain rather poor instruments for investigating practices, especially in rapidly evolving areas;
(b) the comparability and representativeness of the samples of general practitioners selected in the various countries cannot be considered satisfactory;
(c) the rates of responses are possibly informative on a (very moderate) degree of interest on the topic, but impose strong limitations on the interpretation of the findings and on their generalizability.

A perfect blend of merits and limitations seems particularly suitable to address a topic characterized by an important degree of ambiguity and uncertainty, from both the points of view which matter: what is the available clinical and epidemiological knowledge? what is the evidence on the most appropriate models of care organizations? In recent years, heart failure has had impressive therapeutic gains, as demonstrated by a series of major clinical trials, which produced model evidence-based guidelines. It is noteworthy, however, to underline that one of the main positive characteristics of the trials (the high comparability of the recruited populations), which makes their core message even more consistent, is also one of the most critical limitations of the transferability of their results into general practice. The few epidemiological databases which have been produced (with different methodologies and aims) coincide, in showing that the patients who are seen in routine practice (by cardiologists, internists, not to mention the even rarer data from general practitioners) are profoundly different from those of the trials[2–5]. The mean age is higher, the percentage of women is much greater, and the spectrum of co-morbidity is broader and more relevant. What is even more striking is that the totality of the information has been produced far from general practice and nursing care, although sparse parallel evidence in the literature are highly suggestive of a clearly positive additional role of non-pharmacological, nursing interventions in controlling and improving relevant outcome measures[6–7].

The paper by Hobbs et al.[1] (as is often the case, particularly in medicine increasingly fond of measuring the gaps between what should be the standard, and the reality of practice) seems to be interested, and not surprised in the end, in documenting that the coincidence between standards and practice is not impressive. Was the expectation different? Should general practitioners be conceived (homogeneously, across cultures, markets, health settings) as professionals who see their vocation (duty? obligations?) as an exercise of obedience–compliance to ‘external’ standards?

It should be ‘normally’ recognized that the repetitive reposition of guidelines is not an attractive and effective tool for permanent education and even less for producing lasting impact on behaviour. Areas where the traditions of care of those who produce guidelines are widely different from those who are expected to apply them, are at specific risk of proceeding as parallel realities, with only occasional experience and outcomes of cross-fertilization. What are the important suggestions which appear to be recommended by the provocatively ambiguous data of Hobbs et al.[1]? Following and strengthening lines of action and research already developing in the area of heart failure across Europe[8], some strategies to bridge the gap of discontinuity between cardiology and general practitioners could be promoted, to produce new knowledge on unmet needs, more than to claim stricter obedience to ‘controlled’ guidelines.

(1) A first critical caveat: let’s drop from the armamentarium of research, investigations based on questionnaires which explore perceptions, opinions, declared behaviours: not only because the information obtained is hardly reliable, but mainly because it reproduces a cultural model where abstract standardized knowledge is a surrogate for the heterogeneity of practices which reflect the open questions raised by the clinical epidemiology of real patients.

(2) If the issue of transferability of controlled evidence is important, it should be investigated with the same, or at least a comparable investment, of methodological, organizational, and financial resources. Formal cooperative, large-scale groups, representing effectively the different conditions of [dis]continuity of those who care for chronic heart failure patients (cardiology, medicine, geriatrics, general practice, home care) should be established to be able to recruit, follow, and assess populations defined according to broad explicit inclusion criteria, with appropriate numbers, and pre-established evaluation rules and end-points.

(3) To describe, understand, and monitor complex chronic conditions such as chronic heart failure, beyond the standard framework of mainly pharmacological–therapeutic trials, in the heterogeneous scenarios of general practice, an articulated combination of research strategies is needed. These should comprise epidemiological prospective surveys and/or cohorts, pragmatic trials comparing the yield of different strategies of follow-up, more or less formal outcome studies, combined with nested case-control or case-referent designs to look at the degree of avoidability of the hard clinical events which are used as end-points in randomized controlled trials. The critical common characteristics of the variety of
projects to be implemented is the involvement of real general practitioners, with their patients and contexts of care. The active (not simply ‘obedient’) participation in such a research strategy could be seen as the best (and possibly the only) way for developing a critical mass of competences capable of entertaining a truly multidisciplinary dialogue. The rapidly developing and promising biochemical markers of chronic heart failure will certainly contribute to the appropriateness and comparability of the quality of care\textsuperscript{[9,10]}.

(4) The risk (or ‘sin’) of using an evidence-based medicine approach as an instrument of power, and as a powerful confounding tool with respect to the real priorities of practice, has been recognized\textsuperscript{[11]}. To minimize its recurrence, the issue of effectiveness should be addressed with the same philosophy of efficacy: systematic, non-sporadic or occasional, efforts by dedicated networks. An evolution in this direction cannot occur spontaneously: it could only become a reality if it is also part of the official policy of scientific societies, which could act both as pressure groups on public and private sponsors and fund-providers, and as promoters and supporters of the scientific credibility and priority of what should be considered a real new area of research.

For many acute/subacute cardiological interventions, registries (based often on administrative data) have played an important and recognized role in documenting the critical passages from efficacy to effectiveness. This approach could hardly be considered a reasonable resource for chronic heart failure, which on the other hand is a condition which will certainly retain or even increase relevance in public health in the long term.

(5) The contribution of Hobbs \textit{et al.}\textsuperscript{[1]} may be seen as a representative expression of a growing literature on the same topic. What is more important to recall is the even more rapidly increasing number of general practitioners (individuals as well as groups) who, in most countries, are actively involved in clinical and epidemiological research\textsuperscript{[12,13]}. Their networks are ready to integrate those established by cardiologists in recent years. Chronic heart failure could be a perfect opportunity to test the capacity of the complementarity and continuity of two spheres of competence — care, culture — which have so far remained substantially separate. The increasingly broader and bigger population(s) of chronic heart failure patients deserve truly collaborative strategies: all the way through from the controlled trials on (not only pharmacological) efficacy to the controlled assessment of effectiveness. Let’s see whether, when, where, by whom, at national, or international levels, formal steps in this direction become a reality.

G. TOGNONI
Istituto di Ricerche, Farmacologiche ‘Mario Negri’, Milan, Italy

References

\begin{enumerate}
\item McMurray JJV, Stewart S. Nurse led, multidisciplinary intervention in chronic heart failure. Heart 1998; 80: 430–1.
\item Gavazzi A. The ‘Improvement of HF’ initiative to increase awareness and improve the management of heart failure in Europe. G Ital Cardiol 1999; 29: 1445–51.
\item Sackett DL. The sins of expertise and a proposal for redemption. BMJ 2000; 320: 1283.
\item Thomas P. The research needs of primary care. BMJ 2000; 321: 2–3.
\end{enumerate}