Measuring quality of life and assessing technologies are both increasingly prominent in health care systems. This growth has accompanied growing concern over aging populations and health care expenditure growth. Nevertheless, there appears to be unrealized potential for synergy between quality of life research and technology assessment. In this paper, we consider the roles and challenges facing quality of life research in three domains: research—particularly clinical trials of therapeutics; clinical situations and policy-making. We then examine the potential for synergy in these domains and conclude that expanding collaboration will strengthen both fields and intensify their impact in research, clinical practice and policy-making.

Introduction

Health care systems all over the world are facing a difficult but exciting future as populations age and services consume more and more resources. Mapping out the future of health care systems requires attention to both demand and supply, and the fruits of quality of life (QOL) research have a clear and growing role in that process.

In this paper, we hope to share our perceptions of QOL research and roles for its efforts in measuring QOL in research, clinical and policy situations. From this survey, we will explore the potential for expanding links and building synergy between QOL research and technology assessment.

Overview of health care system challenges

Virtually every health care system in the world is undergoing rapid, radical change. In Canada, provincial governments are closing or merging hospitals leading to significant reductions in bed numbers. In the United States, the number of people lacking health insurance is reported to have climbed to over 40 million, and in the United Kingdom, practitioners and providers are still feeling the effects of massive changes in the National Health Service. In short, at virtually every level of health care systems, change and opportunity abound.

Despite the local particulars and impacts of these changes, all share a common urgency, arising from a combination of aging populations demanding increasingly intensive services for longer periods of time coupled with a growing resistance to allocate additional fiscal resources to health care. In several societies, the very sociodemographic groups who demand lower taxes and smaller deficits are those who will fight hammer and tongs to resist any change in the nature of their publicly-financed access to health services. As a result, governments and private-sector payers have shifted attention to cost reduction rather than demand reduction strategies.

To be sure, the challenge inherent in growing numbers of persons living longer is, in a very real sense, the spoils of the war on mortality. For much of the last century, health care services have focussed on mortality reduction, particularly infant and maternal mortality. Fundamentally different now is a growing realization that health services are increasingly required to make a transition from 'mortality reduction at any cost' to 'morbidity reduction in a justifiably cost-effective manner'.

Quality of life research and its instruments and insights have been a significant part of this revolu-
tion's leading edge. Ranging from general measures such as the SF-36, the Nottingham Health Profile and the Sickness Impact Profile through disease-specific measures and utility measures, tools for measuring QOL have increased in number and breadth.²

**Quality of life research: where has it been?**

This increase appears to stem from a significant focus for much of the past two decades on what might be termed 'tool-making': emphasis on creating measurement instruments and scales and upon demonstrating their psychometric properties in terms of constructs such as validity and reliability. Concurrent with this has been an evolution from variously described constructs of QOL to multidimensional constructs of health status, raising questions about which domains will be sampled.³ Accompanying this tool-making has been the question of whether both multidimensionality and specificity can be captured in generic measures, such as the SF-36, or whether they lead axiomatically to disease-specific QOL and a resulting need for lots and lots of QOL instruments and scales.

To survey some of these issues, we shall now consider clinical, research and policy uses of QOL research.

**Clinical use**

A recent editorial in the *Lancet*⁴ criticized QOL measurement for a focus perceived to be excessively quantitative—that the reductionism inherent in a check-off list misses the fundamentally qualitative character of QOL. In fact, one could argue that the reductionism that flows from fascination with psychometrics has limited the clinical use of QOL tools. After stripping away the bureaucracy and facility attending a practitioner-patient interaction, one is left with its fundamentally interpretive nature—patients do not present to practitioners asking for a higher score on a performance measure but rather with an often frightening uncertainty about what is happening to their bodies and lives. In decoding a given patient's presentations and concerns, the practitioners cannot help but interpret the patient's descriptions and actions through filters of medical knowledge and human experience. Might it be the case that the human, interpretive elements of patient-practitioner relationships are threatened by the veneer of 'objectivity' that attends the language of 'scales and instruments and validity'? The irrelevance attending such facades of objectivity is particularly notable if one considers most of the current methods used to measure so-called 'utility'. That a person may, in the abstract, opt for two years less expected life rather than loss of hearing is quite different from the real choices faced by patients and their families. What is the utility preference of a 75-year old woman with lung cancer offered the choice of essentially palliative chemotherapy and its attendant hair loss and vomiting, coupled with the unverifiable promise of a few more months of life? And furthermore, how can she identify or clarify the real conflict arising from choosing among possible outcomes, none of which may be guaranteeable?

Given this reality, the patient or clinician faced with such a decision may be unlikely to reach for a QOL scale, for the simple reason that the stance of patients is still, by and large, a passive one. The active patient, one with a clear set of preferences and the confidence to make a choice has no need of a scale to articulate preferences while the passive patient still says, "Doctor, what should I do?" or "Doctor, do what you think is best".

Moreover, as Gill and Feinstein reported in a recent study of QOL instrument use, only 15% of studies defined QOL and only 13% endeavoured to measure QOL through patient-specific means rather than standard questionnaires.⁶ Patient-related QOL is logically central to the concept of QOL and if QOL is not patient-related, to what might it be related?

The key issue here then, is identifying appropriate indications for a given QOL tool. In the same way that all persons with headache will not have their skulls x-rayed, it seems reasonable that there are situations where QOL instruments may be particularly useful in bringing critical information into a practitioner-patient interaction. Might it be the case that in advancing the importance of QOL as a conceptually desirable outcome of health services, insufficient attention has been paid to the practical question of when a given instrument's use enhances decision-making?

**Research use**

In clinical research, by contrast, QOL outcomes are a growing part of randomized controlled trials, particularly those for therapies targeted at morbidity reduction. The *Lancet* editorial cited earlier⁷ noted that the number of references to QOL increased three-fold between 1990 and 1994, and that 9% of these references also mentioned randomized trial. In the USA, it has been ten years since the FDA first recognized QOL benefits as admissible outcomes for