Health outcome measures

A well known joke among surgeons is that “the operation was a success but the patient died”. This encapsulates a generalised clinical phenomenon; doctors tend to focus on a unidimensional outcome measure, either the presenting symptom or the success of a specific intervention. However, we all accept that health is a multidimensional experience, incorporating physical, psychological, and social components. Over recent years, a growing industry of health outcome measures has developed for use in randomised trials and observational studies. Some of these measures are generic and can be used both in healthy as well as patient populations, whereas others are disease specific. This interest has even spread into the neurological community as evidenced by a new text explicitly titled “Outcomes in neurological and neurosurgical disorders.”

There are several important reasons why such measures should be used. Firstly, they can highlight the limitations of therapeutic interventions. A multicentre randomised placebo controlled trial of tacrine in Alzheimer’s disease noted significant benefits on clinical measures of cognition, but this was sadly not translated in any consistent effect on quality of life measures. Secondly, they can illustrate mismatches between clinical and patient perceptions about their disease. Patients with multiple sclerosis rated mental and emotional health as their most important domains of wellbeing, whereas neurologists and neurosurgeons emphasised physical function. Finally they capture additional aspects of the disease process which may be missed by more specific measures. A comparison of the PDQ-39, a quality of life measure developed for Parkinson’s disease, showed strong correlations between measures of physical function with both the Hoehn and Yahr or Columbia rating scales. However, there was no correlation between its measure of social health with either scale.

The paper by Karlsen et al (this volume, pp 431–5) examines various clinical features found in patients with Parkinson’s disease on patient’s self reported quality of life. Their findings, not surprisingly, show that motor disability as indicated by the Schwab and England score, and levodopa dose, are important predictors of quality of life. More interestingly, they also highlight the equal importance of depression and sleep disturbances; clinical areas that are usually less thoroughly examined in a busy clinic compared with the motor aspects of the disease. Interestingly, depression was as disabling in terms of social isolation as motor disability. Sleep disturbances, which were common, also independently contributed to the self-reported mobility measure, as well as the Schwab and England score.

Some caution is required in not overinterpreting these results. Many of the measures are highly correlated, have varying degrees of measurement error which could produce spurious results, and in some cases variables may be intermediary factors which mediate the effect of impairment on quality of life. Nevertheless, this study does highlight potential ways that current management of patients with Parkinson’s disease could be improved. Although most therapeutic efforts are focused on producing newer antiparkinsonian drugs, it is possible that paying greater attention to the psychosocial aspects of this disease may have a big impact on improving quality of life.

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