

Editorial**What has oral health related quality of life ever done for us?**G. Tsakos¹, P.F. Allen² and J.G. Steele³¹Department of Epidemiology and Public Health, UCL, UK; ²Cork University Dental School and Hospital, Ireland; ³School of Dental Sciences, Newcastle University, UK

Over the past 50 years, there has been a significant increase in life expectancy. At the population level, there has been a shift from a high prevalence of acute illness, with accompanying mortality, to a high burden of chronic illness in an aging population. There are within and between country variations in this trend, and there is evidence that the “improvement” in health has not been experienced equally across individual countries or regions of the globe. There is often significant morbidity associated with the consequences of chronic illnesses, and policymakers face major challenges in funding healthcare systems dominated by chronic disease management. While healthcare has been traditionally dominated by the measurement of pathological processes, it is now recognised that healthcare outcomes cannot be comprehensively assessed by objective measures alone. Whilst control of disease is important at individual and population level, the agenda for healthcare now includes the need to improve life quality as well as longevity. It is recognised that, for many people, the elimination of the consequences of disease is not achievable and such cases may benefit from shifting the focus of healthcare to palliation of symptoms rather than cure.

To reflect this change, models of health have moved from a purely biological to more of a bio-psycho-social basis that places emphasis on outcomes rather than simply disease (Kaplan, 2003). Over the past 30 years, a variety of so-called “health-related quality of life” measures have been developed to enable patient-based assessment of health status to be incorporated in decision making. Oral health has been part of this trend and in 1996, a conference was held in North Carolina to discuss the plethora of newly developed “oral health related quality of life” (OHRQoL) measures that had emerged in the preceding years (Slade, 1997). This conference marked the beginning of an era of gradual acknowledgement of the importance of this field and the widespread use of these measures in research and practice. Like anything new, they have been perceived as the solution to many problems, some of which were clearly beyond the scope of these measures. The various instruments claim to measure the same construct but their focus is not without variation, illustrating the conceptual multiplicity of the instruments. They are not without their problems, as we will discuss.

Nearly 20 years on from the North Carolina meeting, it seems appropriate to consider where we stand in relation to the measurement of “oral health-related quality of life”. Many of the OHRQoL measures described in 1996 have not been widely, or ever, used. Three of these measures (OHIP, OIDP, GOHAI) have stood the test of time and are still widely used, with the OHIP being the most reported measure. But overall, this research field has followed a rather “cautious” and technical approach and the literature contains numerous examples of cross-cultural application and validation of these measures. While this is important, it logically leads the debate to more relevant questions. Have we used them to address important research questions for clinical and public health practice? Have we used them in health policy? Have they been used and the resultant data reported appropriately? Answering these and similar questions would provide a good assessment of whether this field has lived up to its initial promise and whether we have used OHRQoL measures to their full potential.

OHRQoL measures are not free from limitations. It has been argued that they are not true quality of life measures, as most measures only capture negative impacts. They either have no theoretical framework or have been based on the International Classification of Impairment, Disability and Handicap which has now been superseded by the International Classification of Functioning, Disability and Health. Of further relevance is the notion that disease, health and quality of life are distinct concepts, as illustrated by the so-called “disability paradox” (Albrecht and Devlieger, 1999) where some patients with apparently severe signs of chronic illness actually report good quality of life scores. It is highly debatable whether a single measure can capture all these aspects.

There is also a related question of terminology; is “oral health related quality of life measures” an appropriate term? Unlike in medicine, there has yet to be a concerted critique of so-called state of the art quality of life measures used in dentistry. At the very least, such academic scholarship might have resulted in their use in a harmonised way. Gill and Feinstein (1994), among others, have argued for the need to demonstrate that these measures actually capture events that are meaningful and important to patients. In a critique of the most widely used OHRQoL measures, Locker and Allen (2007) argued

that current measures mostly establish the frequency of functional and psychosocial impacts of oral disease, but do not demonstrate the true significance of these events on quality of life. They suggested that further qualitative work was required to establish the full impact of oral disorders on quality of life. Such development work could make these measures conceptually relevant by identifying which construct(s) they capture and how they map to theoretical frameworks.

Notwithstanding these concerns, there is now an expanding volume of literature using OHRQoL measures in population studies and clinical trials. Data from population studies in particular have highlighted the negative impact of disease on quality of life. It is particularly helpful to have subjective health status measures incorporated into national population surveys, as intuitively this should help decision makers identify particular needs and target resources accordingly. Similarly, there is merit in using OHRQoL measures as outcomes to assess the effectiveness of both clinical and public health interventions. The use of such measures in trials has been less frequent than in population studies but they can, and at times have, been used effectively in these settings. All of these seem appropriate and relevant applications for the use of such instruments.

A more difficult consideration is whether the use of OHRQoL measures has actually influenced policy decisions. A number of national epidemiological surveys have now incorporated these measures and therefore have robust data sets concerning the symptom status associated with oral disease. The possibility of targeting resources towards those most likely to benefit from particular interventions is one of the suggested benefits of their use. In the absence of any evidence to suggest that this has happened, and assuming that 20 years is deemed sufficient time lag for an influence on policy decisions, there is a need to explore whether this is due to ignorance of available measures and their significance, apathy, limitations in how the data are reported or simply a reflection of the disconnect between scientific measurement and policy decisions. It may be all of these but we argue that the uncritical reporting of OHRQoL scores may have contributed to the difficulty in interpretation and the resulting lack of usefulness of that information for policy makers.

Finally, the reporting of data may be something that requires greater attention. For example, there is a tendency in the literature to present data from clinical trials in traditional ways, such as means and medians, and to make claims according to the statistical significance of differences between groups. The use of OHRQoL measures in the evaluation of implant therapy for edentulous patients provides an example of the reporting and interpreting pitfalls. The authors of these studies argue that there is substantial benefit for edentulous patients provided with implant retained prostheses compared with conventional dentures on the basis of 3-6 months of follow-up. These data have been used in support of a consensus statement arguing that implant retained overdentures should be a standard of care for edentulous patients (Thomason *et al.*, 2012). Important questions of reporting and interpretability arise. For example, is a short-term follow up of this nature appropriate to inform a policy decision with

potentially significant financial costs? More importantly, can substantial benefit really be determined on a measure expressed using scores that are intrinsically meaningless as they are not directly related to specific clinical or population profiles? Furthermore, is the within-subject data sufficiently homogenous or does the overall mean improvement in OHRQoL mask the existence of a minority in the treatment group that did not improve or deteriorated following an intervention? Finally, how can we tell if a certain significant difference is meaningful clinically or from a public health perspective? Interpretability concerns extend to all applications of OHRQoL measures, not just intervention studies. In line with this, we have advocated the use of the minimally important difference (MID) to provide a benchmark towards interpretability and suggested minimum standards for reporting and interpreting OHRQoL measures (Tsakos *et al.*, 2012).

Another potential way of dealing with these interpretation issues is to use economic analyses to put a monetary value to the reported quality of life impact. Alternatively, the impact of an intervention is assessed by calculating the number of patients that need to be treated for one patient to report a clinically meaningful (as opposed to statistically significant) benefit from the treatment intervention. If cost effectiveness of interventions can be demonstrated in terms of quality of life impact, then advocacy for resource allocation becomes more convincing.

Much has been achieved in terms of development and validation of subjective measures of oral health. It is now time to critically re-evaluate the status of the science, expand on its applications to clinical and public health practice, and refine measures and how data are reported in line with identified shortcomings in the current knowledge. Getting out of the basic technical tasks and moving in different and more complex directions will bring out a true subject-centred approach and result in outcome measures that represent the views and feelings of the people.

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