

Health-related quality of life and the transformation of symptoms

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Abstract This paper traces the development of health-related Quality of Life instruments over the last half century. It identifies the emergence of key components of quality of life measurement in other health status questionnaires between about 1950 and 1980 and their formalisation in Quality of Life instruments in the mid 1980s. The common developmental thread that linked these Quality of Life instruments and their precursors was the identification of 'distal symptoms' that represented the impact of illness beyond its immediate bodily manifestations. The measurement of distal symptoms through Quality of Life instruments also served to detach symptoms from their customary patho-physiological referent. Other contemporary examples of these free-floating symptoms reinforce the argument that the nature and meaning of symptoms has been transformed over recent decades.

Keywords: quality of life, questionnaires, measurement, pathology

Early in the 19th century a doctor would often ask a patient 'Do you have any pain?'. The purpose of the question did not involve courtesy or concern – whatever personal sympathy the doctor may have had for the patient's plight – but was directed at eliciting a symptom that might indicate an underlying disease. At the end of the 20th century another level of signification was added to the question: the response to 'Do you have any pain?' now also pointed to a new construct, the patient's (health-related) Quality of Life. How did the meaning of pain for medicine become broadened from its original pathological referent to encompass a new less tangible concept that was located somewhere in a social rather than biological realm? This paper explores the transformation in the meaning of symptoms this shift implies by exploring the origins and development of formal measures of Quality of Life. The emergence and success of Quality of Life measures, it is argued, represent a relocation of illness to the patient's social world.

Symptoms and pathology

Two centuries ago a new medical framework emerged from Parisian hospitals that stressed the centrality of an intra-corporal pathological lesion for a proper understanding of illness

(Ackerknecht 1967). This lesion was indicated by symptoms – what the patient reported – and signs, what the doctor found on clinical examination. Together, symptoms and signs allowed the doctor to infer the existence of a diseased structure or process that was otherwise invisible to the eye of medicine. Thus the two key elements of a new clinical method, eliciting patients' histories and physically examining their bodies, allowed the clinico-pathological correlation, as Foucault (1973) termed it, to be used to 'read' the body of the patient for the presence of disease. Medical science thereby came to construe a patho-physiological basis for any body sensation reported by the patient – with the corollary that any symptom/sensation could be used to infer the presence of that same patho-physiological disturbance.

Under the new framework of pathological medicine, the essential dialogue in clinical practice was between the physician and the lesion. The lesion 'spoke' through the patient's symptoms and confirmed its presence by those physical signs that the skilled clinician could elicit. The physician wanted to 'hear' the lesion speak (through symptoms) but during the early decades of the 20th century there was a realisation that the patient could distort the process of clinical communication with irrelevant interjections or, worse, inappropriate interpretations (Armstrong 1984). The task then was to overcome or neutralise the bias introduced by the idiosyncratic patient reporting symptoms inaccurately. The physician had to ensure as far as possible that the reported symptom represented the truth of the lesion, for example by seeking to avoid leading questions. As Sir Maurice Cassidy, Senior Physician to St Thomas' Hospital, observed in 1938: 'What a lot of valuable time would be saved if our patients could be taught that all we want to hear from them is an account of their symptoms, as concise as possible and chronological!' (p. 177).

Concern with the accuracy and relevance of the patient's own reports crystallised a new object for medical scrutiny in the space previously occupied by intra-corporal pathology. Not only could symptoms be construed as indicators of disease but also as the idiosyncratic expression of some aspect of patienthood. Thus, by the middle of the 20th century the clinical interrogation – or interview as it was to be renamed – began to recognise two tasks. One was the traditional elicitation of symptoms so that, together with signs and investigations, the nature of the pathological lesion could be inferred; the other was the use of symptoms to access the patient's mental world. In part, the latter was achieved by direct questioning about the patient's psychological and social life; in part, it involved re-reading the patient's 'distortion' of symptoms as a subtle mechanism for accessing the mind. A symptom might therefore point to a lesion or a psychological state, or both. In effect, as Balint (1955) was to note some years later, the symptoms of illness did not bear an immutable relationship to some invariant internal pathology: 'A great number of patients . . . offer or propose a variety of illnesses to the doctor. The variety available to any one person is limited by his constitution, upbringing, social position, conscious or unconscious fears, and conceptions of illness'. (1955: 684) This new analysis did not break the link between symptom and pathology that had sustained the medical model of disease for over a century but it did indicate emerging fault-lines. The uncertain status of symptoms was further compromised by the emergence of a new measurement technology that might render symptoms 'objective': the questionnaire.

Questionnaire technology

The idea that questionnaires could be used to elicit information was an old one. At least since the beginning of national Censuses at the turn of the 19th century, an informant was

found able to give structured information to a series of written questions. But such instruments elicited objective 'facts' about an external world. This use of questionnaires to collect information about an individual's external circumstances continued into the early 20th century as illustrated by some of the classic surveys of poverty (Marsh 1982). But it was only with the emergence of Opinion Polls in the inter-war years of the 20th century that questionnaires were used to elicit a more subjective response that somehow described an internal property of an individual's mind. By the mid-20th century questionnaire 'technology' was sufficiently developed to claim to be able to access a broad swathe of human mental functioning.

Questionnaire-based health surveys that were conducted towards the end of World War II to assess how well the population was bearing up to the strains of warfare (Box and Thomas 1944) included a simple item that assessed the perceived health status of respondents. This question could not be construed as a precise medical enquiry as it made no assumptions about underlying disease, rather it was conducted in the spirit of the pre-war opinion polls, in this case inviting views about the respondent's health. Interest in the population's 'opinion' about its own health found later expression in the concept of illness behaviour (Mechanic and Volkart 1960, Mechanic 1962) that explored why patients chose to take symptoms to their doctor, but this opinion seemed to have no necessary relationship with a person's actual health status as only medicine was competent to judge whether those symptoms indicated real disease. It was in fact a reassessment of the status of such symptoms that enabled the emergence of subjective health indicators some decades later but in the immediate post-war years the pioneering work in this area was conducted by psychiatry.

Capturing symptoms

Early psychiatric instruments had emerged alongside psychological questionnaires as personality-based tools to enable screening for job assignment. During WWII the need to assess large numbers of combatants and non-combatants meant that these instruments needed to be simplified to ask the question: 'Can this person do the job?'. Further, these new screening instruments were based on identifying neuroses (rather than personality), a relatively new category of affective psychiatric morbidity that had been growing in importance since early in the 20th century.

War-time screening instruments showed that neuroses could be measured relatively easily across large groups of people. In consequence, after the war, a number of research projects were established to examine the mental health of whole populations. The wartime psychiatric screening instruments had been constructed for young (mainly conscripted) men so an instrument that was intended for the whole community needed a fresh start. In 1957, the Sterling County Study devised a new instrument for this purpose, the Health Opinion Survey (HOS) whose core, nevertheless, comprised 15 questions taken from the US Army's Neuropsychiatric Screening Adjunct with additional questions for neurotic discrimination. The final instrument contained 20 questions that sought to discriminate between respondents' levels of mental distress.

The early success at measuring a population's mental health can be ascribed to a unique feature of psychiatric disease. Resonating with the 18th century relationship between illness and symptoms that preceded the 19th century ascendancy of pathological medicine, the very nature of (neurotic) psychiatric disease was that the symptom was, in the main, the 'pathology'. Patients who reported themselves as being highly anxious could be described as having

anxiety disorder and those reporting depression could be labelled as having (clinical) depression. True, there were other associated symptoms, some of them physical or 'vegetative', but they all pointed to a diagnosis that was, in essence, a cluster of symptoms. This meant that psychiatric diagnosis, unlike the identification of organic disease in other branches of medicine, rarely required a clinical examination as there were no signs to elicit: the psychiatric instrument could therefore attempt to reproduce the psychiatric interview. Thus enquiries such as 'Do you have loss of appetite?' or 'Are you ever bothered by nervousness?' (contained in HOS) were exactly the sorts of questions that psychiatrists would pose in face-to-face consultations. This gave the instrument creators a clear idea of the sort of item content they had to include and allowed straightforward validation by comparing the results of the clinical interview and the questionnaire-based simulated interview.

In as much as 'psychological symptoms' were also 'subjective' it was relatively easy, later, to incorporate them into measures of subjective health status. Questions such as 'I look forward with enjoyment to things' or 'I have lost interest in my appearance' (from the Hospital Anxiety and Depression Scale of 1983) could become both indicators of psychiatric pathology but also measures of patient experience. It was then but a small step to integrate these sorts of questions into later formal Quality of Life measures (e.g. 'How much do you enjoy life?' or 'How satisfied are you with the way your body looks?' from the WHOQOL-100 of 1994). Yet perhaps more important than providing some basic items for later instruments, these psychiatric questions provided a model for eliciting other symptoms by questionnaire.

For non-psychiatric disease, symptoms were usually only preliminaries, guides or rough indicators of what the underlying pathology might be. At the end of 'history-taking' when all the symptoms had been reported by the patient the clinician would establish a differential diagnosis – the range of possible pathologies that might explain the pattern of symptoms. Often these were many in number and the role of the clinical examination and subsequent laboratory and radiographic investigations was to narrow down the possibilities until it became clear which diagnosis matched the patient's clinical picture. Therefore, while it was possible to construct a checklist of physical symptoms for patients to complete (see below), the particular configuration of selected symptoms could not easily translate into a diagnosis as in the psychiatric field. In consequence there seemed little point in collecting symptoms from populations without the necessary 'translation tables' to transform them into diagnoses as was possible in the large mental health surveys where 'caseness' could often be identified.

Although it seemed at first that questionnaires had limited value in the diagnosis of non-psychiatric disorders it was soon realised that they could at least be used for population screening or for monitoring the impact and severity of the disease over time. This approach was seen particularly in the measurement of one of the commonest symptoms, pain. Pain had been a key marker of the presence of pathology. Patients' reports of joint pain, chest pain, abdominal pain, etc., alerted the clinician to the possibility of pathology at those anatomical sites. History-taking involved an elaborate dissection of any reported pain: when did it happen, what made it worse, where did it move to, how severe was it, what type of pain was it, and so on. Each characteristic of the pain fed into the differential diagnosis to narrow down the pathological possibilities. But these clinical procedures could, in part, be replicated by a questionnaire that could pose the same questions as the clinician. The resulting symptom pattern could then be fed into aspects of clinical decision-making.

The experience of pain collected by a questionnaire could be used as an initial screen for pathologies such as coronary heart disease that usually presented with pain (Rose 1965). Also, change in reported pain levels could be used to follow the course of the disease in those conditions for which there was assumed to be a close association between symptom and pathology. If the symptom worsened, then this suggested that the disease was also

getting worse. For both screening and monitoring the connection between the pain as symptom and the underlying pathology was not in doubt: the two were inextricably linked together as signifier and signified. But the possibility of eliciting and recording pain by questionnaire made the symptom at once both more objective and more subjective: more objective because the questionnaire score gave it an existence independent of the patient's report, more subjective because it pushed an aspect of patient experience more centre-stage. Questionnaires such as the Rose Chest Pain Questionnaire of 1965 and the McGill Pain Inventory of 1975 therefore contributed to a further loosening of the symptom-pathology axis.

If the symptom of pain could be measured by questionnaire then why not other symptoms as well, particularly ones that were distressing for patients and/or that might indicate the course of the underlying illness? Symptom checklists began to emerge both as components of more ambitious instruments for use in diagnosis and prognosis but also in their own right as ways of capturing the patient's experience of illness. Symptom questionnaires could be used to identify or follow the course of respiratory disease (Fairbairn *et al.* 1959), hypertension (Bullpitt *et al.* 1974) or gastric ulcer (Keighley *et al.* 1976). The NIH Stroke Scale of 1983, for example, was essentially a symptom-rating scale; similarly the Canadian Neurological Scale of 1986 (for patients with acute stroke) asked the observer to note level of consciousness, orientation, speech, motor function, etc., while the Varicose Vein Questionnaire (1993) asked about pain, swelling, itching, rash, and 'appearance that cause you concern'.

Symptom checklists started as an efficient means of 'screening' for disease as, according to the logic of medicine, symptoms indicated the presence of pathology. But the questionnaire began to distil symptoms from the general clinical picture and to stabilise them in a formal record that could be compared across and within individual patients. Further, the shift from signs and laboratory investigations to reports of symptoms as guides to the progress of disease represented a new emphasis on the patient's perspective that became more and more important in post-war clinical practice. The clinical gaze (Foucault 1973), which for over a century had been firmly fixed on the pathological lesion, began to form new structures of perception, of organising and thinking about the nature of illness.

Activities of Daily Living

Despite the value of a pathological diagnosis in guiding treatment, many diagnoses did not give a clear indication of the clinical severity of the disease. This was particularly true for many chronic illnesses: several patients might have rheumatoid arthritis, for example, but the common diagnostic label concealed a great diversity of patient disability. One obvious method for determining severity involved examining pathological indicators – rheumatoid factor or X-ray appearance, for example – as revealed by investigations and visualisation techniques because these would reveal the extent of pathological 'damage'. Yet surprisingly for the logic of a clinical method, based on reducing illness to the pathological lesion, indicators of pathological severity were increasingly found to be often poorly related to the symptoms and disability as experienced by the patient (Lawrence *et al.* 1966). This realisation at once struck at the core role of symptoms as both product and indicator of pathology: if symptoms did not infer pathology what did they point to? More practically, if markers of pathological damage could not be used to predict a patient's experience then that experience would have to stand on its own as an alternative reading of the severity of disease. The questionnaires through which physical functioning was measured became known generically as measures of activities of daily living (ADLs) (Katz *et al.* 1963). Basically, they listed

everyday activities and the patient or a carer or a health professional would score the patient's ability to carry out each named activity.

ADLs provided a useful way of assessing disease severity but they also enabled comparisons across diseases. A patient with rheumatoid arthritis could now be compared with a patient with multiple sclerosis and one with stroke, all scored on the same ADL measure. In effect, an ADL provided a new form of illness categorisation replacing the nosology of internal pathological processes with an ordering of physical function. Inability to walk upstairs ('Did you have trouble either walking one block or climbing one flight of stairs?': Arthritis Impact Measurement Scales of 1980) or scoring the level of dependence-independence for bathing, dressing, toileting, continence and feeding (Katz *et al.* 1963, Mahoney and Barthel 1965), for example, enabled previously separate diagnostic labels (arthritis, stroke, injury, etc.) to be reclassified along a new dimension of function. But as well as offering an innovative nosography, ADLs challenged the accepted place of the symptom in medical thinking.

For pathological medicine the disease produced clinical symptoms – pain in arthritis, for example – which acted as diagnostic and prognostic markers. The ADL, however, was not focussed on these immediate manifestations of pathology but on a more downstream effect of the disease and its symptoms: how did arthritic pain reduce joint mobility and how did the latter affect climbing stairs? Thus, inability to climb stairs was as much a 'symptom' of arthritis as pain, only it was more distanced from the pathology. ADLs therefore established a new realm of 'distal symptoms' removed from the immediate indicators of the intra-corporal lesion and more embedded in the patient's everyday world.

The idea of disease in biomedicine had only extended from its pathological nucleus to the body's boundaries, to perturb the function of some corporal extremity, a system in which symptoms only represented a preliminary 'reporting' mechanism. Distal symptoms, however, radiated out from corporal space into the everyday world of the patient and provided an important adjunct to classical symptoms and symptom lists. The latter might be debilitating but how did they affect the patient? Ability to undertake everyday activities provided a new way of reading the manifestations of disease, from being in hospital through not being able to work to being unable to pursue specific physical tasks.

The social dimension

The concept of the ADL marked a major transformation in medical thinking. It both extended the limited notion of the clinical symptom from an immediate effect of the pathological lesion to a more distant consequence for physical functioning in everyday situations and also revived an older symptom-based classification of illness. Yet ADLs expressed only one step in the process of moving symptoms downstream. Limitations of everyday physical functioning were only of significance in that they interfered with involvement in social activities – a framework that was also developed in the WHO's classification of impairment, disability and handicap (Wood 1980) to explore the impact of disabling disease on social functioning.

The 1948 WHO definition of health (a state of complete physical, mental and social well-being) had already highlighted the importance of adding a social function dimension to those of physical and emotional functioning when considering health in the round. Indeed, there seemed a universe of human needs and attributes that could be included in any psychosocial domain of health including self-esteem (Schwartz 1975), loneliness (Plutchnik *et al.* 1975), personal adjustment (Carp 1975), adequate heating and purpose of

living (Kennie and Arnott 1973), hobbies and recreation (Dempsey *et al.* 1975), and sexual activity and lifestyle (Levy and Wynbrandt 1975). This focus on psychosocial life as an important component of health further reinforced the significance of distal symptoms, increasingly distanced from the patho-physiological underpinnings of traditional clinical markers of disease.

With the addition of indicators of social participation to ADLs the impact of disease could now be mapped on the social body. Joint pain, for example, was a symptom of arthritis, but joint pain interfered with mobility which in its turn interfered with social functioning. These extended symptoms had no clinical significance in terms of being aids to diagnosis of the underlying lesion in the individual patient as they were too non-specific, though they did prove useful in the epidemiological context, for example, in estimating the burden of (chronic) illness (*e.g.* Harris 1971). Indeed, they provided a solution to the problem of transitivity that had bedevilled the summation of different diagnostic groups in population medicine: instead of trying to equate the 'worth' of one case of arthritis with one of stroke, say, the epidemiologist could use the common currency of distal symptoms collected in an ADL. But the next task was to bring together all these distal symptoms into one all-encompassing instrument.

The Quality of Life instrument

In 1970 Carlens and his colleagues tried to capture 'quality of life' by constructing a 'vitagram' that plotted length of survival against a simple index measuring activity and symptoms for 115 patients undergoing treatment for lung cancer. In the same year Tofler (1970), a cardiologist, suggested that 'life units' be used to measure the value of replacing heart valves. These could be calculated by multiplying years of post-operative survival by a measure of quality of life – for which he suggested a simple five point scale of functioning running from a life without restriction to a life virtually confined to a hospital bed. Then, in 1973, Aris and his colleagues compared two heart valve prostheses in a (non-randomised) study of 420 patients. The main research question was: Did the new valve really extend life? But in addition, the researchers asked patients by post, telephone or in face-to-face interviews about the quality of their life post-operatively. Patients were given three choices, improved, unchanged or worsened. The study found there was no survival difference between the two prostheses but the researchers were gratified to note that over 90 per cent of all patients reported quality of life improvement. That simple question – what is your quality of life? – had captured the impact of distal symptoms.

The idea of Quality of Life as an indicator of social state or goal of social change had emerged in the 1970s (Armstrong and Caldwell 2004) but its operationalisation in medicine was effected by populating the construct with the increasingly (conceptually) unattached symptom. Thus the notion of Quality of Life both summarised and constituted the range of distal symptoms that a patient might experience. Some of the new Quality of Life instruments that began to emerge with increasing frequency during the 1980s did incorporate the single item 'How would you rate your current quality of life?' but more commonly their basis lay in the four measures – symptom lists, mental health status, ADLs and social functioning – that had been developed in the preceding two decades. Each of these dimensions had objectified symptoms and emphasised those with distal characteristics. The McMaster Health Index Questionnaire for example, conceived in 1971, took some physical function items from the St Thomas' Health Survey Questionnaire and the Katz ADL measure and placed them alongside social function and emotional wellbeing taken from the Social

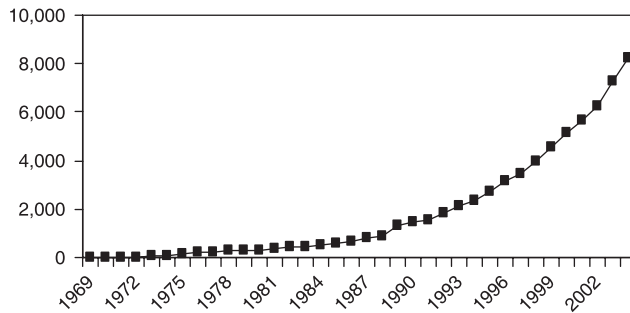


Figure 1 *Annual PubMed Quality of Life Citations*

Readjustment Rating Scale. The more widely used Sickness Impact Profile of 1976 involved sifting through 312 items derived from patients before settling on 136 items covering symptoms (e.g. tiredness), psychiatric illness (depression, confusion), physical activities (mobility, ADLs) and social activities, including work and hobbies. And Kaplan's Index of Well-being of 1976 captured these function levels in their relation to symptom complexes – mobility, physical activity and social activity – scoring them from 1 to 0 (dead).

The underlying four-dimensional format of the classic Quality of Life instrument was now complete, and between about 1980 and 1995 gradually consolidated its hold over medical outcomes research and practice. (The significant increase in publications exploring quality of life is shown in Figure 1.) Lists of clinical symptoms and items on mental health status were married to ADLs and questions on social functioning. The Spitzer Quality of Life Index of 1981, for example, reduced the measure down to four one-item dimensions of an ADL, support, outlook (calm and positive v confused, frightened, depressed, anxious), plus a visual analogue scale on which patients could offer their own summary Quality of Life score. The COOP/WONCA charts of 1987 included all four dimensions (as well as a question on 'overall' Quality of Life). In the most widely used general instrument from this period, the SF-36 of 1992, 36 items apparently covered a wide-range of different topics (divided into eight dimensions) but the basic format of physical, mental and social functioning together with symptoms underpinned the apparent heterogeneity of its constructs (e.g.: respectively, 'Does your health now limit you in (climbing one flight of stairs)?', 'Have you felt downhearted and blue?' 'Has health interfered with your social activities (like visiting with friends, relatives, etc.?)' and 'How much bodily pain have you had during the last 4 weeks?').

One of the defining characteristics of quality of life was patient assessment (as against earlier instruments in which clinicians often made judgements on a patient's behalf) of their own health status in terms of distal symptoms. Sometimes the component questionnaire roots of these new instruments were easy to identify as they were little more than symptom questionnaires or ADLs despite titles that suggested something more inclusive. The Health Assessment Questionnaire of 1980, for example, set up to measure patient outcome in arthritis, stressed the importance of social and mental functioning alongside physical capacity but, perhaps inevitably, largely consisted of ADLs. But whatever their narrowness in capturing only a small range of distal symptoms these various questionnaires – symptom checklists, ADLs, etc. – were increasingly labelled as Quality of Life instruments. Even those instruments set up explicitly as 'subjective health measures' soon became proto-measures

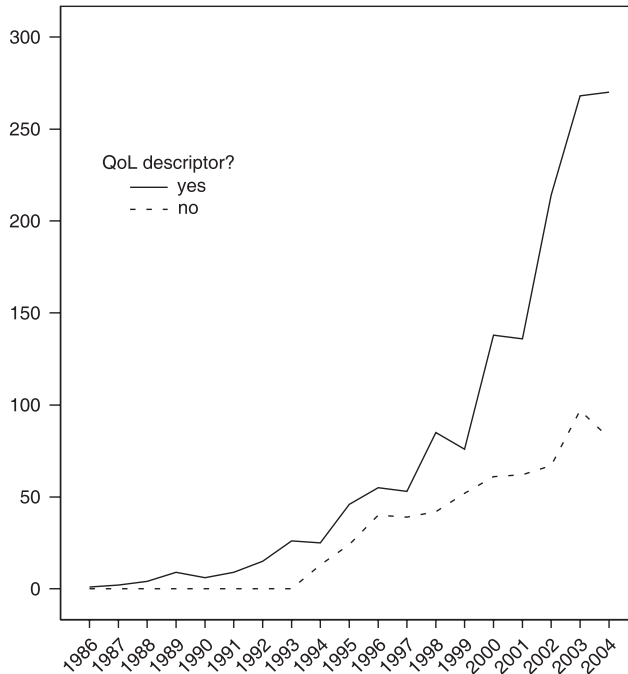


Figure 2 Sickness Impact Profile citations described as QoL measure?

of quality of life, particularly in retrospect. Figure 2 for example shows the number of papers using the Sickness Impact Profile that describe it as a subjective health measure and as a Quality of Life instrument. Since about 2000, the latter has been increasingly dominant.

Conceptualising quality of life

The emergence of Quality of Life instruments involved a pragmatic attempt to capture distal symptoms without much attention to what quality of life actually meant. Indeed, the very success of the concept of quality of life in colonising instruments that measured such varied aspects of health-related experience as mood, pain and mobility further jeopardised the uncertain coherence of the underlying construct. What was the common understanding that underpinned such a diversity of questionnaires? Did quality of life represent simply an opportunistic sample of items from a universe of distal symptoms or did it assume something more focused and meaningful?

Some Quality of Life measurement reflected the continuing idea that all symptoms, whether clinical or distal, originated in the pathological lesion. Thus, a specific disease, arthritis, say, might cause proximal symptoms – pain, swelling, movement restriction, etc. – and distal symptoms such as disability and social handicap. The former could be recorded by the doctor in the clinic while the latter could be captured in a Quality of Life instrument. The latter, in effect, mapped out the radiating impact of the pathology on the patient's wider world: the elicitation of proximal symptoms re-stated the traditional link between disease and its manifestations, but then by eliciting more downstream symptoms allowed the full

consequences of a disease-type on a patient's life to be portrayed. For example, the European Organisation for Research and Treatment of Cancer (EORTC) developed not only a Quality of Life instrument for patients with cancer but also a number of sub-modules that could capture the specific distresses that occurred with particular cancer types. The core EORTC instrument (QLQ-C30) introduced in 1993 consisted of 30 items that followed the customary pattern of exploring symptoms, disability, and psychological and social state. The 'add-on' QLQ-LC13 of 1994 for patients with lung cancer, however, consisted largely of proximal clinical symptoms (such as 'Did you cough blood?' and 'Have you had hair loss?') that might be expected from the existence of lung cancer inside the patient or from the effect of its treatment. In that sense, Quality of Life measurement represented simply an extension and formalisation of the theory and method of established clinical practice.

While disease-specific instruments could anchor symptoms (whether proximal or distal) to the underlying disease processes, generic instruments that attempted to capture distal symptoms irrespective of their pathological basis were more difficult to place within a conceptual framework. Many generic instruments, such as the Nottingham Health Profile of 1980 (Hunt and McEwan 1980), were derived from statements collected from healthy populations about the meaning of 'health' for the respondent. This strategy had two implications. First, it implied that the construct being operationalised was located in the psychological and social worlds of those surveyed populations and second, that there was some sort of equivalence between 'health' and (health-related) quality of life. Thus, not only were (distal) symptoms located in a social rather than biological world but health itself was re-based in terms of social meanings rather than pathology.

Health economists exploited the social derivation of Quality of Life measurement to link social value to health states. As part of standardising health outputs, health economics needed to quantify the quality of health experience that would be traded for duration of life. People could be asked to make these trade-offs directly using techniques developed from the early 1950s such as standard gamble and time trade-off (Brazier *et al.* 1999) but these were tedious and difficult to complete. So, when formal Quality of Life instruments appeared, economists saw an opportunity to simplify their work by asking members of the public to trade-off various Quality of Life scores against increase in life expectancy. This produced Multi-Attribute Utility Scales in which the weighted scores assigned to different items were derived from elicitation of patients' preferences. These scores in their turn enabled the social value of a particular quality of life state to be calculated – most notably in Quality Adjusted Life Years (QALYS) (Williams 1985). This approach could be effected either by adding preferences to an existing instrument or by devising a new one with preferences built-in such as the Rosser disability-distress scale of 1972, the Index of Well-being of 1976 (later renamed the Quality of Well-being Scale), the Health Utility Index of 1982 and the EQ-5D of 1990. The core of the latter consisted of a five-item questionnaire (covering mobility, self-care, usual activity, pain/discomfort, and anxiety/depression) so was relatively easy to transpose into social values.

By relating distal symptoms to the social value of any health gain, Quality of Life instruments further detached symptoms from their pathological referent and linked them to a set of social preferences rather than an illness. There were debates about whose values were being used to anchor the symptoms captured in the Quality of Life instrument but preference measures were noteworthy for establishing a new association that made symptoms a measure of social and economic value and, in turn, key determinants of resource allocation across healthcare systems.

Another solution to the conceptual problem of quality of life was to construct individualised instruments such as SEIQoL (McGee *et al.* 1991) in which patients themselves identified

relevant dimensions of their own quality of life then ranked and scored them. This produced an individualised score for everyone that was rooted in the patient's own idiosyncratic social world. A further illustration of the increasing detachment of distal symptoms from the biological underpinning of disease was the contemporary discovery of the 'response shift' phenomenon (Breetvelt and Van Dam 1991, Sprangers 1996, Sprangers and Schwartz 1999) in which it was noted that Quality of Life scores were often more closely related to patients' adaptive cognitive processes than to pathology. Thus for many patients quality of life could improve despite apparent worsening of the underlying disease state as the meaning of the illness experience was constantly recalibrated in line with the patient's coping strategies.

The attempt to connect distal symptoms to an underlying construct did not succeed in producing a universal solution. Whether it was a re-affirmation of the symptom-pathology link or the new attachment to some attribute of a population or individual coping strategies, there continued to be criticism of the less-than-coherent theoretical framework of Quality of Life measurement (Rapley 2003, Cummins 2005). Yet this incoherence reflected the fundamental transformation in symptoms that was occurring. A generic (health-related) Quality of Life score was a measure of illness (through distal symptoms) that, importantly, mostly floated free of any link with diseases inside the patient's body: a patient with no discernible pathology could have poor quality of life and conversely patients with serious debilitating or fatal illness could report very good quality of life.

Placed in a wider context the free-floating distal symptoms of Quality of Life measurement were but one manifestation of a more general separation of symptoms from their traditional pathological referent during the final two decades of the 20th century. Concurrent with the emergence of Quality of Life instruments medicine discovered 'medically unexplained symptoms' whose key characteristic was their disconnectedness with pathology. Whereas abdominal pain, for example, was classically produced by and therefore used as an indicator of abdominal pathology, the symptom was increasingly found to exist without an underlying pathology: the patient reported pain but medicine could find no underlying physical cause. Such unattached symptoms were perplexing for medicine, yet their prevalence seemed widespread (Nimnuan, Hotopf and Wessely 2001). Chronic fatigue syndrome (or ME), Irritable Bowel Syndrome, fibromyalgia, and so on represented a challenge for the traditional medical model that had explained symptoms in terms of their relationship to pathology. Like the proliferating distal symptoms that Quality of Life instruments captured, medically unexplained symptoms reached out towards new conceptual anchors far removed from the body's patho-physiological processes.

The transformation of symptoms

Only a few decades ago the task of medicine would have been expressed in terms of improving health or relieving suffering and the practical manifestations of these rhetorical aims would have been observation of death rates or changes in the biological dimensions of disease (lowered blood pressure, resolution of pulmonary consolidation, reduced white cell count, etc.). This has all changed. Health and suffering have become increasingly encoded in a new concept, quality of life that is measured, in its turn, by the Quality of Life instrument. But this major change in the purpose and goal of medicine masks a more fundamental realignment of illness and experience. Notwithstanding the views or feelings of individual doctors, the logic of biomedicine had subjugated patient experience (in the form of the symptom) to illness (in the form of the pathology). As the underlying basis for illness was held to be

a pathological lesion then identification and treatment of that lesion was the formal aim of clinical practice (though in the absence of identifiable lesions major sectors of medicine such as psychiatry and primary care had remained symptom focused). In this framework, the symptom was a mere indicator of the underlying problem, an epiphenomenon in relation to the core of illness that often existed beyond patient perception. The symptom was a product of the lesion, a signal of the existence of the latter that trained clinicians could identify and interpret so as to begin the process of inferring the exact nature of the hidden pathological forms that constituted the basis of illness.

The conceptualisation and measurement of quality of life began to change the relationship between symptom and illness that had dominated the discourse of clinical practice since the 19th century. On the one hand, as described above, symptoms increasingly detached themselves from their pathological anchor and began new attachments to aspects of the patient's psychosocial world. On the other hand, for many areas of clinical practice symptoms seemed increasingly less important in the search for the underlying lesion. For example, for the screening programmes introduced in the second half of the 20th century symptoms were an irrelevance as the task was to identify pre-symptomatic lesions. Equally, the major advances made in diagnostic technologies – from novel biomarkers to new visualisation techniques – seemed to offer a more 'objective' approach to diagnosis than reliance on the vagaries of symptom reporting.

But symptoms still existed for patients. They experienced both immediate clinical symptoms and their distal consequences. The Quality of Life instrument captured these experiences and gave at least equal weight to the 'downstream' effects of illness such as impaired mobility and disrupted marital life. Quality of Life instruments therefore functioned to divorce the experience of illness (through symptoms) from the identification of its biological basis; Quality of Life measurement located the illness experience in the everyday world of the patient. And whereas clinical medicine had applied a nosographic approach to patient suffering, attempting to categorise and organise the patient's symptoms in terms of underlying pathologies, Quality of Life did not classify according to underlying types but rather scaled patient experience across a continuum. Quality of Life instruments were therefore both derived from and related to populations, a normalising approach that compared health over time and over individuals.

The idea of quality of life is now a fundamental goal of medical intervention and health-care although the formalised instruments for its measurement that emerged two decades ago have been largely restricted to research settings. But in that quality of life has been used as a core evaluative criterion for assessing new technologies, its impact on clinical practice is not only to be measured in rhetorical terms but also indirectly in the flood of clinical interventions that themselves have been evaluated in terms of their impact on distal symptoms. In effect, Quality of Life measurement has given symptoms a new and extended meaning and has consolidated the patient's self-report as a central component in the definition of health and illness.

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Acknowledgements

This paper derives from an ESRC funded project 'Quality of life as an innovative health technology', grant number L218252008.

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