

Editorial

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## Patients' needs, satisfaction, and health related quality of life: Towards a comprehensive model

Mohsen Asadi-Lari\*<sup>1</sup>, Marcello Tamburini<sup>2</sup> and David Gray<sup>1</sup>

Address: <sup>1</sup>Division of Cardiovascular Medicine, University Hospital, Nottingham, NG7 2UH, UK and <sup>2</sup>Unit of Psychology, Istituto Nazionale Tumori, Via Venezian 1, 20133 Milan, Italy

Email: Mohsen Asadi-Lari\* - msxma@nottingham.ac.uk; Marcello Tamburini - tamburini@istitutotumori.mi.it; David Gray - d.gray@nottingham.ac.uk

\* Corresponding author

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With the publication of its 100<sup>th</sup> paper, the new open access Journal *Health and Quality of Life Outcomes (HQLO)*, achieves a significant milestone. Launching a journal in this field was not just a challenge with respect to nomenclature, [1] but also provided a forum for disseminating research which emphasises the unique contributions as well as the inter-relationships among determinants of health, provision of care, and outcomes. So far, prominence (as measured by the number of scientific manuscripts accepted for publication) has been given mainly to the unique contributions of health-related quality of life (HRQL). Other determinants like health needs and satisfaction have sporadically been considered [2-7]. A few additional papers have focused on approaches to detect ill health. In this editorial we would like to explore the relationship between needs, satisfaction and quality of life, identify gaps in the current knowledge base, and encourage future research in these areas.

### Clinical approach

The World Health Organisation (WHO) in 1948 defined health as a "a state of complete physical, mental, and social well being not merely the absence of disease or infirmity" [8]. While this definition is comprehensive (though rather utopian and ambitious) it clearly indicates what *should* be the goal of health care intervention. Medical professionals however tend to focus more narrowly on a medical model of health care -a history and examination- followed by investigation and treatment, and finally clinical measures of successful outcome. This approach has been criticised for producing a paternalistic doctor-patient relationship [9,10]. The relative success of a given

health care intervention may differ significantly from a patient perspective vis-à-vis the health care provider's perspective. When this occurs we may ask ourselves; Has a health need been met? Was the care process satisfactory? Has the burden of disease on the patient's quality of life been minimised?

This traditional approach to patient assessment, using clinical and laboratory evaluation, is largely based on observer ratings by health professionals. In the 'medical model', there is an optimal level of functioning and everybody below this could be assumed to suffer ill health. However if these cases are examined carefully, physically-disabled individuals could be found with better quality of life than individuals with optimal functioning, as quality of life refers to a broader concept of health than has traditionally been defined. Modern medicine is slowly beginning to recognise the importance of the perspective of the patient in health care and more investigations are needed to understand the importance of the inter-relationships among health needs, satisfaction, and quality of life.

### 'Need': conceptually complex

No consensus seems to exist about the meaning and concept of 'need' in health, sociology and political literature [11-13]. The ambiguity of the concept of 'needs' and enormity of the task imposed upon practitioners has made the transition from service-led to needs-led much harder [14]; this vagueness is more apparent when a specific need fails to fall neatly into 'health care' or 'social care' domains, each of which is correlated with the other. Patients with depreciated perception of health status have

more social needs [4], thus meeting social needs may have a direct impact on general health status, which eventually falls into the health domain, perhaps indicating the 'holistic nature' of needs [14]. For example, cancer patients may have a need to better understand their diagnosis and the specific prognosis. However, they may feel guilty about interrupting a busy General Practitioner, and so their needs are not met. This may raise the patient's level of anxiety, which in turn may worsen their emotional health status [6,15,16].

Need has a broad spectrum, as the range of human experiences is quite large. The main focus in Wen and Gustafson's paper [6] was on emotional problems, which despite its importance in perceived HRQL, consists of just one part of the whole concept- there are more subscales. Apparently, the physical scale has been ignored in their models, as are other components of the physical and emotional domains such as quality of sleep, pain and discomfort, social contacts and overall perception of quality of life perception.

'Need' may have a direct effect on satisfaction with care but the direction of the relationship is not clear. For example, patients may have a need for more or better information on some aspect of health. If this need is unmet, it may result in dissatisfaction with services. Alternatively, the better informed patient tends to have higher expectations and so be dissatisfied with care [6]. Both of these scenarios directly influence quality of life [5].

A current definition of need that has been occasionally published in the National Health Service (NHS) documents indicates that need is the 'capacity to benefit from health care services'. However this definition may be too restrictive as "legitimate" patient needs might be limited to those that can be easily addressed within existing health services and that are considered 'medically necessary', maintaining the medical model which experience suggests has proven unsatisfactory in meeting patient needs.

The pressure of political self-preservation obliges health decision makers to handle health issues with no further increase in global health budget, thus they prefer to manipulate and introduce rather strict and somewhat artificial definitions to justify shortages in resources devoted to the health sector. Unfortunately using a more restrictive definition of 'need' masks the larger amount of genuine health needs of the population. Satisfying all of these desired health needs would, most certainly, require more monetary resources.

The challenge therefore is to identify and target patients' genuine needs. Mobilising resources to meet these needs would certainly avoid further expenses, keep patients sat-

isfied with services, and lead to better quality of life. At the moment, there is no single definition of genuine health needs precisely within the context of public health policy, yet it makes sense to describe this inherently complex issue as 'what patients – and the population as a whole-desire to receive from health care services to improve overall health'. Even this definition may leave practitioners 'open to making judgement based on implicit knowledge, rooted in professional training and values, office culture and assumptive world' [17].

### **Patient satisfaction surveys**

The modern approach to healthcare seeks to engage the attention of both patients and the public in developing healthcare services and equity of access, but this is not easy to achieve, requiring time, commitment, political support and cultural change to overcome barriers to change [18,19]. Improvement in selected aspects of health care delivery through quality assurance and outcome assessment has been driven by political expediency. While this is important, a 'bottom up' assessment of patient satisfaction seems preferable if service improvement is to be translated into outcomes meaningful to patients, especially improved quality of life [20,21].

Satisfaction can be defined as the extent of an individual's experience compared with his or her expectations [22]. Patients' satisfaction is related to the extent to which general health care needs and condition-specific needs are met. Evaluating to what extent patients are satisfied with health services is clinically relevant, as satisfied patients are more likely to comply with treatment [23], take an active role in their own care [24], to continue using medical care services and stay within a health provider (where there are some choices) and maintain with a specific system [25]. In addition, health professionals may benefit from satisfaction surveys that identify potential areas for service improvement and health expenditure may be optimised through patient-guided planning and evaluation [19].

Critics draw attention to the lack of a standard approach to measuring satisfaction and of comparative studies [26,27] and so the significance of the results of those surveys that do exist in the literature is often ignored. There is less controversy with respect to *clinical outcome* measures, as health-related quality of life (HRQL) is not only widely regarded as a robust measure of outcome assessment but also is extensively used in several clinical areas [28,29].

Patient satisfaction is considered by some to be of dubious benefit in facilitating the process of clinical care, as patients have no specific clinical expertise and are -perhaps- readily influenced by non-medical factors; in

addition, there are few reports on the reliability of satisfaction surveys [19,30,31]. Nevertheless, satisfied patients are more likely to comply with medical treatment and therefore ought to have a better outcome [23].

### **The role of health-related quality of life**

Reliable (and increasing) evidence exists about the robustness of the predictive value of patients' perception of their own health status [32,33]. Some HRQL tools are able to assess post-MI patients' perceived health status and there is a significant correlation with conventional clinical assessments like the treadmill exercise test [34,35], or with functional classification such as the New York Heart Association (NYHA) scale [36]; however reports are inconsistent [37,38]. It is noteworthy that the correlation coefficient for treadmill-induced angina on tests one day apart was 0.70 [39] and for patient-reported angina was 0.83 when SAQ was applied three months apart [40]. The shift to the patients' viewpoint, however, is pessimistically asserted to be inevitable in chronically ill or dying patients as there is no option for further clinical assessment [41].

There is growing evidence indicating that 'quality of life assessment' can be considered as adjuvant to clinical and physiological assessments in many chronic conditions, particularly cancers [42] and coronary artery diseases [43]. This approach is postulated to be the 'gold standard' in the evaluation of healthcare services and outcome assessment. The large variety of generic and disease specific instruments can confuse researchers contemplating the most appropriate tools for quality of life investigation. As a general rule, however, the combination of generic and disease-specific HRQL questionnaires provide complementary information [3,44,45].

### **Relationship of satisfaction, quality of life and health needs**

Wen and Gustafson [6] proposed an interesting model of the relationship between health needs, satisfaction with care and quality of life in cancer patients. Their research makes a compelling case for us to reassess the concept of needs assessment and better explore its relationship with outcome measurements, like clinical endpoints, quality of life, and satisfaction with care. The association of health needs and health-related quality of life and also satisfaction with health services have been acknowledged in cancer patients, oral health and cardiac patients in *Health and Quality of Life Outcomes* [3-5,7], and a few in other journals [46].

A comprehensive evaluation of health care should ascertain a patient's expressed health needs [47]. Identification of the needs of individuals (and of the local population), whether through formal needs assessment or some surro-

gate, is an essential first step towards optimising the use of allocated resources.

The correlation between health needs and health-related quality of life scores might have potential benefits in routine clinical investigation, too, where comprehensive care is targeted. Administration of appropriate HRQL tools in clinics, surgeries or health centres may detect areas of health care needs worthy of health professionals' closer scrutiny. For example, a patient with an impaired Short Form Physical Component Score [33] or physical dimension (SAQ-Phys) may perhaps be distinguished not only as being at high risk in terms of clinical end points [48], but also as a vulnerable patient who might have difficulty accessing health care services, for which extra care (such as after hours services or ambulance transport) may be required. Similarly where the satisfaction component in the SAQ yields a lower score, cardiac care teams must be aware of potential shortcomings in the delivery of care and investigate reasons for any dissatisfaction; even provision of information about the nature of cardiovascular disease or its treatment may improve the satisfaction score.

Health-related quality of life tools have the potential to identify specific and general health needs. First, components of disease-specific HRQL tools are more likely to be associated with specific health care needs. Second, measuring HRQL provides outstanding insight towards approaches that may lead to improved quality of care [40]. Third, the administration of 'off-the-shelf' quality of life tools affords a rapid screening test to identify both populations and individuals who warrant a more detailed health needs assessment.

A common critique of quality of life tools in clinical research is that data are 'soft' and less reliable than traditional clinical assessment or physiological measurement. Nevertheless, both generic and disease-specific tools can detect subtle clinical changes quite precisely [40], especially in cardiac disease [49]. Some are concerned that HRQL tools may not precisely identify the most important problems yet, from an economic and existential point of view, it is conceded that patients' perception has equal validity and legitimacy to that of physicians [41]. English language-based quality of life tools have been tested in a wide range of diseases; overall in clinical practice and in health service research, they have proven so useful that both generic and disease-specific tools have been translated into a variety of other languages for wider application.

Basing health care needs on quality of life scores, however, necessarily incorporates several sources of uncertainty due to factors such as age, sex, social class and individual

patient's health status. In addition, quality of life tools may fail to distinguish between health problems and the desire to get professional attention [50].

Despite the documented relative merits of HRQL tools in various clinical and research settings, these tools may not detect individual health needs in depth. For example, assume a coronary artery patient who has attended in a cardiac rehabilitation session with an impaired emotional score in the MacNew (Quality of Life after Myocardial Infarction) or sleep disorder in the Nottingham Health Profile (NHP) questionnaire: can we distinguish the background reason for this impairment? Is it due to (at worst) heart failure disturbing depth of sleep or simply because the patient has teen-aged grandchildren who afford little time for rest? At this stage, an in-depth needs assessment could reveal the background explanation, which may warrant changes in medical treatment or the provision of social support. Any comprehensive modelling must include both needs and outcome assessment to evaluate the whole process of care in individual and population levels. The optimum approach, perhaps, could be a combination of needs and outcome assessment, preferably at individual levels [41].

### Comments/ Discussion

While a large body of literature exists and continues to expand on generic and condition specific health-related quality of life assessment theory and applications, and to a lesser degree patient satisfaction, the inter-relationship between needs, satisfaction, and quality of life remains ambiguous; there is no consensus over the actual contribution of these measures in modelling a comprehensive health care arrangement.

As we reflect on the current state of research in these areas, a number of challenges confront us:

1. Are the current research efforts in the evaluation of health status, needs, satisfaction and quality of life appropriately balanced?
2. Should research on health status and quality of life be terminated or should the emphasis on traditional clinical outcomes (such as survival) be reduced? Which should prevail?
3. To what extent can quality of life be used as a proxy or surrogate for satisfaction and/or the needs of patients? Just as clinical indicators have been used as surrogates for quality of life [51], are we in danger of similarly mistaking health need as a surrogate?
4. What is the evidence for the psychometric properties of the instruments used to evaluate satisfaction and needs?

5. Have studies of patients' satisfaction been conducted but not published because of negative results, poor validity and reliability and responsiveness of the instruments developed (eg high levels of ceiling effect with high levels of satisfaction due to patients' fear of giving negative evaluations)? Or studies which could not be published because non-validated instruments were deployed, to assess patient satisfaction, not only wasting scarce hospital resources but also delaying changes in health service delivery by local health authorities.

We have addressed these questions to a selected number of researchers (most of them editorial board members of the Journal or Authors of articles published in HQLO; see Table 1). Their answers/comments are reported in the following sections and provide HQLO readers with interesting thoughts about the direction of future studies.

The concept and approaches of needs assessment, satisfaction, and HRQL seems fundamental to 'good practice', 'quality care', and 'community participation' at a time of greater patient empowerment. However, resource constraints on one hand and medical expectations on the other may jeopardise the impact of the patient's perspective.

It is our hope that drawing attention to the importance of the interaction of patients' health needs, satisfaction and health-related quality of life will stimulate further research to produce valid and reliable data and perhaps new investigational tools which take all these non-medical factors into account.

#### **Are the current research efforts in the evaluation of health status, needs, satisfaction and quality of life appropriately balanced?**

My view is that the best, most accurate quality of life data and conclusions should point to unmet needs and should be closely associated with satisfaction. Therefore, rather than seeing this as a competition for limited resources, potentially spawning a short-term feeding frenzy on the nature of these relationships, I view it as a call for better appreciation for how existing quality of life evaluations point to appropriate treatment directions and patient satisfaction with care. Recently, several researchers have turned their focus to such application of existing tools.

**David Cella**

Why is 'balance' needed? And what is an appropriate balance? I find this sort of question a bit pointless, as researchers will do what researchers do anyway. But the question lacks explicit criteria in terms of which to discuss the matter. **Anthony Culyer**

**Table 1: Appendix. Authors of the comments**


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Mark J. Atkinson, PhD  
Senior Outcomes Research Scientist  
Worldwide Outcomes Research  
La Jolla Labs, Pfizer Inc.  
San Diego, CA, USA  
Anne Brédart, PhD  
Unite de Psychiatrie et D'Onco-Psychologie  
Institut Curie, Paris Cedex, France  
Cinzia Brunelli, ScD  
Unit of Psychology  
Istituto Nazionale Tumori, Milan, Italy  
David Cella, PhD  
Professor, Psychiatry and Behavioral Science  
Research Professor  
Institute for Health Services Research  
and Policy Studies  
Northwestern University  
Director, Center on Outcomes,  
Research and Education  
Evanston Northwestern Healthcare  
Evanston, IL, USA  
Anthony Culyer, CBE, BA, Hon DEcon, FRSA, FMedSci  
Professor and Chief Scientist  
Institute for Work and Health  
Toronto, ON, Canada  
James T. Fitzgerald, PhD  
Department of Medical Education  
University of Michigan Medical School  
Ann Arbor, MI, USA  
Samuel C. "Chris" Haffer, PhD  
Director, Medicare Health Outcomes  
Survey Program  
Centers for Medicare & Medicaid Services  
Baltimore, Maryland, USA  
Michael E. Hyland, PhD, CPsychol  
Professor of Health Psychology  
School of Psychology  
University of Plymouth, UK  
Robert M. Kaplan, PhD  
Professor and Chair  
Department of Family  
and Preventive Medicine  
University of California  
San Diego, La Jolla, CA, USA  
Richard Kravitz, MD, MSPH  
Professor and Director  
UC Davis Center for  
Health Services Research  
in Primary Care  
Co-Vice Chair for Research  
Department of Internal Medicine  
Sacramento, CA, USA  
Ruth McCorkle, RN, PhD, FAAN  
Director of the Center for  
Excellence in Chronic Illness Care  
School of Nursing, Yale University  
New Haven, CT, USA  
Stephen P McKenna, PhD  
Director of Research  
Galen Research, Manchester, UK  
Brian Ott, MD  
Department of Clinical Neurosciences

**Table 1: Appendix. Authors of the comments (Continued)**


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Brown Medical School  
Providence, Rhode Island, USA  
Luis Prieto, PhD  
Health Outcomes Research Unit  
Lilly, S.A., Madrid, Spain  
Ewa Roos, PT, PhD,  
Associate Professor  
Dept of Orthopedics  
Lund University Hospital  
Lund, Sweden  
Rob Sanson-Fisher, PhD  
Professor of Health Behaviour  
Faculty of Health  
University of Newcastle, Australia  
Richard Shikiar, PhD  
Senior Research Scientist and COO  
MEDTAP International, Inc.  
Seattle, WA, USA  
Davide Tassinari, MD  
Department of Oncology, City Hospital  
Rimini, Italy  
Andrew Vickers, PhD  
Integrative Medicine Service  
Memorial Sloan-Kettering Cancer Center  
New York, USA

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I don't think it is a good idea to dictate which areas of research should be continued and discontinued. The best research stems from investigator initiation. **Robert M. Kaplan**

We need to make our assumptions clear. We, as researchers and clinician, categorise the world so as to make sense of the world. We divide it into manageable parcels. One of these parcels is health related quality of life (HRQL); another is patient satisfaction; and yet another is patient need.

However, these are our interpretations, they are not necessarily what goes on inside the patient. Consider the following truisms:

1. When patients respond to a questionnaire, they are actually responding to the individual items of the questionnaire. The researcher then sums those items in one way or another.
2. The patient's response to individual items reflects (a) what the researcher thinks the item is measuring and (b) many other things as well, some of which the research may be aware of but others are unknown.
3. Measures of satisfaction reflect items measuring referring specifically to some defined aspect treatment (the selection is made by the researchers). Measures of HRQL

include a range of emotional and physical aspects (again selected by the researcher) but typically without referring to the actual treatment received. Both these kinds of item are highly correlated with trait negative affect (e.g., neuroticism), which is itself often a component of HRQL scales. There is often some overlap in the wording of items from different kinds of scale, so not surprisingly satisfaction, HRQL and personality scales inter-correlate quite highly.

4. Perception of need depends on trait negative affect, as well socially constrained expectations. If all of your neighbours have donkeys but not cars, then you don't 'need' a car. But if your neighbours all have two cars, then you may be dissatisfied with one. The idea of 'genuine needs' referred to in the editorial is one of those fictions – it depends on who decides what is genuine.

5. Perceptions about need have an impact on satisfaction and HRQL – the more you need the less satisfied you are. People with high self-expectations are more likely to be depressed. Is it better to be happy and live in a gutter, or unhappy and live in a palace? Are health professionals encouraging patients to be unhappy palace dwellers by showing them how much better their health could be?

6. The above shows that outcome is conceptually far more complex than is often thought and from the patient's perspective, the distinction between satisfaction, HRQL and needs is by no means straightforward, and furthermore assessment is associated with value judgements which are often not made explicit.

7. Despite all these problems, my personal view is that the really is no alternative to questionnaire based assessment of patients satisfaction, HRQL and need. All health care resource allocation is based on value judgements. We cannot avoid resource allocation, and we cannot avoid value judgements. Outcome assessment forces us to make these assumptions a little more explicit. Perhaps if I am making recommendations for the future, it is that we should make the assumptions on which our scales are based far more explicit than we do at the moment. **Michael E. Hyland**

My reflection on this question and above is: how encourage, help communicating, sharing viewpoints between various specialists (e.g. clinicians, psychometricians,...). There are still barriers between them and this may cause unproductive research. Clinicians need to understand the relevance and usefulness of working on "soft" data besides traditional medical endpoints. This is far to be achieved. **Anne Brédart**

One area where we do think there is imbalance is that quality of life and health status instruments are often eval-

uated cross-sectionally, for example, by comparing scores-between patients with early and late stage disease. There is less research looking at the responsiveness of instruments to change following treatment; in particular, there is insufficient research on how to develop instruments that are maximally sensitive to change. **Andrew Vickers**

I think one needs to have more research on assessing the contribution of general health and specific disease components to quality of life, and how this contribution varies between cultures, ethnic groups, genders, and age groups. More research on health related quality of life as an outcome measure in clinical trials is needed. Pharmaceutical companies for example are still reluctant to use quality of life as an outcome due to perceptions that the available measures lack reliability and, to a lesser extent, validity. There is also reluctance to use clinical indicators as proxies for quality of life, which I think is justified, given our present state of knowledge. **Brian Ott**

The issue is not so much balance as continuing to explore the connections between these concepts and to be explicit about their relationships to one another. Health status, needs, satisfaction, and quality of life are empirically related. Are they conceptually distinct? Not yet. As the editorial points out, needs are subjective, satisfaction is related to "needs", and measures of quality of life should (but rarely do) incorporate the values of patients rather than investigators. As Sullivan points out [52], the outcomes movement is changing the physician's job description from a focus on patients' bodies to a focus on their lives. We better get it right. **Richard Kravitz**

The editorial covers a number of different types of health outcome that could be assessed; health status / health-related quality of life (HRQL), quality of life (QoL), patient satisfaction and health needs. Each has a different purpose and these different outcomes are not dependent on each other – though they may be correlated to a greater or lesser extent [53]. Research into HRQL is more extensive than that into the other outcomes but it is questionable whether it has reached a particularly high quality in most cases. Further research is required to improve the assessment of HRQL and into assessment of the other outcomes. There is no reason why, for example, development work on the assessment of QoL should be sacrificed to increase efforts to assess patient satisfaction. However, it seems likely that market forces will govern where research efforts are directed.

As the different types of outcome are based on different measurement models and have dissimilar aims, one type of outcome cannot (and should not) be seen as a surrogate for another. The science of patient-reported outcome measurement has been hindered by the practice of taking

measures of one type of outcome and implying that they assess a different outcome. Instruments such as the Sickness Impact Profile [54], Nottingham Health Profile [55] and SF-36 [56] were developed as health status instruments for use in population surveys (as indicated by their authors). Over the years they have become commonly referred to as 'QoL' measures, as the need arose to assess this construct in clinical trials. As a consequence of their widespread use in this context, relatively few 'true' QoL instruments are now available, limiting our ability to determine the true overall impact of disease and its treatment on the patient.

Care must also be taken in using the terms 'health needs' and 'needs' interchangeably. The issue is analogous to that of equating HRQL with QoL. HRQL restricts consideration to issues that are capable of influence by health services [57] and, consequently, misses many important aspects of a patient's QoL which may benefit from an improvement in health status. As defined in the editorial, 'health needs' are also restricted to ways in which 'health services can improve overall health'. This could lead to the conclusion that health needs have been satisfied while neglecting the fact that this has been at the cost of other needs. For example; economic needs may be increased as a result of paying for treatment, emotional needs may be adversely affected by certain pharmaceutical treatments or appearance needs may deteriorate following radical surgery.

A more holistic approach to 'needs' can be taken, following from Hunt & McKenna's work on needs-based QoL. Proponents of the needs-based approach postulate that life gains its quality from the ability and capacity of the individual to satisfy their needs (either inborn or learned during socialisation processes) [58]. Functions such as employment, hobbies and socialising are important only insofar as they provide the means by which these needs can be fulfilled. In this approach it is taken as axiomatic that QoL is high when most human needs (not just health needs) are fulfilled and low when few needs are being satisfied. Again, focusing only on those needs that can be influenced by health services will give an incomplete picture of their value to patients.

In order to evaluate the benefits of any service it is essential to have high quality instruments with good psychometric properties. For most diseases such instruments are lacking for all types of outcomes listed above. Extensive instrument development work is required in each of these outcome areas. Consequently, it is too soon to talk of achieving a 'balance' or reducing efforts into any one particular type of patient-reported outcome. **Stephen P. McKenna**

Each of the three broad areas addresses a potentially different and important field. Many measures of quality-of-life reflect the views and judgements of the experts. The respondent is asked to indicate whether or not they can perform or feel in a certain way. Dependent upon the answer a judgement is made usually on statistical basis that they have what do not have a high quality of life. In Needs analysis the respondent is often asked for their judgement about whether or not they have a need in a particular area. This allows the respondent themselves to determine priorities and perceptions of what assistance they require. It is this area of research which currently requires more effort on development of both the theoretical and pragmatic aspects of measurement. **Rob Sanson-Fisher**

More than balancing current research in the evaluation of health status, needs, satisfaction and quality of life, the integration of these scientific researches in the assistance process is, in my opinion, the most important challenge that is currently set to the health agents. **Luis Prieto**

Since the mid-1990s there seems to have been an increase in research focusing on health status, satisfaction, and quality of life as independent concepts. Very little seems to have focused on needs. Even fewer (if any) efforts have attempted to study the inter-relationships between health status, needs, satisfaction, and quality of life. **Chris Haffer**

***Should the research focus on health status and quality of life be reduced or should the research on traditional clinical outcomes (such as survival) be reduced?***

Rather than reducing either, we should continue to strive for combining them in meaningful ways that each "side" understands and values. **David Cella**

Why these two alternatives? I would like to see more of both, but especially more on discriminating between the characteristics of the main Health Related QoL measures, their empirical significance, and their usefulness to organisations such as NICE. (Any sensible answer to this question has to begin by asking 'what the research is for?'). **Anthony Culyer**

I have read the editorial with interest but also with some confusion. After some thinking I find my confusion might arise from the fact that in orthopaedics we deal with diseases that you do not die from (at least not primarily). This applies to your open question 2, research on QOL or survival. That is not applicable to my area, if we do not take prosthesis survival into account. This is how orthopaedic surgeons have assessed the success of total joint replacement for years. Generally, assessing QOL in musculoskeletal disease seem the most appropriate in clinical studies since the correlation between the patients perspec-

tive and impairments such as radiographic status is poor.  
**Ewa Roos**

Which area should "pay" for an increase in the number of studies on needs and satisfaction assessment? In my opinion, we have too many disease targeted QOL measures. Although these measures are sometimes sensitive to clinical change in specific populations, they do not clearly guide us toward overall better outcomes. **Robert M. Kaplan**

The degree of focus on health status or Health Related Quality of Life (HRQL) measures compared to more traditional clinical outcomes depends on a number of factors. Typically, if the disease state and the outcomes of treatment can best be reported by the patient (e.g., migraine or depression/anxiety), there is a greater dependence on Patient-Reported Outcomes (PROs) than clinically defined endpoints. A second consideration is whether achieving a particular clinical endpoint is the primary objective of a medical treatment. In palliative care, for example, patient comfort and well-being may be favored over aggressive chemotherapies that might provide a limited extension of life. PROs may also be given equal weight in situations where the costs of treatment are considered against the degree to which such treatments provide some larger societal benefit. In Europe, for example, QALYs are a routine part of formulary decisions and patient access to competing treatments. In contrast, the market access in the USA is less centrally determined and to some degree diverse market forces determine medication availability. Thus a variety of cultural and clinical factors need to be considered when addressing this question and advances in outcomes research are not by any means uniform. **Mark J. Atkinson**

I think there is no white/black answer. Perhaps the question would be: in which contexts (type, stage of disease, treatment side effects), should health status and QoL studies be expanded? **Anne Brédart**

In our view this is not an either / or choice. Both can be measured. Where more thought and research is required is how to combine results from different types of endpoint. For example, what if in a clinical trial one group experiences improved survival, but worse quality of life? What if an intervention affects a clinical outcome, such as a pain score, but does not appear to have an important effect on quality of life? **Andrew Vickers**

This question begs a Solomonic response: both "subjective" measures such as health status and quality of life and "objective" measures such as morbidity and mortality are critically informative, but in different ways. Creating a parsimonious set of generic health measures absent a

larger set of disease-specific measures is extremely seductive but ultimately misguided. The reason is that medical care can extend lives and improve function but cannot, ultimately, make people happy. **Richard Kravitz**

It is difficult to make a judgement about this issue without having a clearer idea about the clinical topic which is being addressed. For example in the area of cancer control that has not been a clinically significant improvement in mortality for some types of cancer. Here the research focus should continue to be on health status, perceived need, and quality-of-life until the interventions exist which will substantively increase the length of life. When this occurs there will be a need to balance the length of life with the quality of that experience. **Rob Sanson-Fisher**

The challenge, again, is in the integration of these two ways of health assessment. Despite the quality-adjusted life year (QALY) continue to represent the paradigm of the integration of the biomedical and the psychosocial models, this indicator has been criticised on technical and ethical grounds. A salient problem relies on the numerical nature of its constituent parts. The appropriateness of the QALY arithmetical operation is compromised by the essence of the utility scale: while life-years are expressed in a ratio scale with a true zero, the utility is an interval scale where 0 is an arbitrary value for death. In order to be able to obtain coherent results, both scales would have to be expressed in the same units of measurement. The different nature of these two factors jeopardises the current meaning and interpretation of QALYs. Further steps in the integration of different health dimensions, like quality of life and survival, are thus necessary. **Luis Prieto**

Rather than viewing these research foci as being in competition, I believe it is more beneficial to view each as complimentary. Both bring unique value to and are essential in providing effective patient care. In other words, they both measure different components of the same phenomenon and both are necessary to maximize positive patient outcomes. **James T. Fitzgerald**

Although there has been an increase in health related quality of life studies over the last decade, there remain major gaps in the literature. Decisions about areas of priorities and the balance of studies must be driven by the research questions to be answered. There continue to be too many isolated studies, with small samples; rather than multi-site investigations combining samples using standardized measures with established protocols. We also need additional studies related to methods, such as determining the best times to measure quality of life in relation to the critical events we are trying to capture. Evidence related to ethnically diverse populations is just beginning to emerge and as our world becomes smaller with the use



of increased technology, these studies will only enrich our interventions.

As our knowledge base grows, clarity will evolve about how HRQL relates to other variables. It's important we design studies that help to clarify the mechanisms to effect predictors and outcomes. Clinically, standardized HRQL measures can enhance screening patients for clinical problems and monitoring them for changes; but overall this process will not take the place of asking patients what they want and what helps to improve their health. With the increased opportunities to do collaborative research across continents, it is a time to increase our efforts to do HRQL research not to reduce them. However, our studies must be theory driven, well designed, multi-site, and build on our previous work. **Ruth McCorkle**

Neither should be reduced. Instead incentives should be provided which would encourage researchers to undertake studies on the undeserved topics mentioned above. Incentives could be: financial (providing money to support the work), educational (encouraging students to undertake dissertations and theses in the areas), or professional (thematic journal issues dedicated only to publishing research on particular topics). **Chris Haffer**

***To what extent can quality of life be used as proxy or surrogate for satisfaction and/or the needs of patients? Is there a danger of making the same mistakes as in the when clinical indicators were used as surrogates for quality of life?***

Yes, this kind of risk always emerges when one tries to use a related concept to estimate another. **David Cella**

I would say, not at all to the former and only to the extent that it correlated with a conceptually correct version might the answer to the second be affirmative. **Anthony Culyer**

In orthopedics, measures of satisfaction have been used to determine the outcome of total joint replacement. I am however concerned about the single question that has been used. From unpublished data I know that patients reporting to be satisfied with a total knee replacement may have revision surgery within a year. This is bothering when considering validity of the satisfaction question. **Ewa Roos**

I do not think that QOL measures can serve as surrogates for satisfaction and needs. In fact, it is important to maintain independence. For example, it would be valuable to demonstrate that satisfaction goes up when outcomes improve. However, evidence is necessary to demonstrate this relationship. **Robert M. Kaplan**

Important conceptual and practical distinctions exist between HRQL and treatment satisfaction (and more broadly, patient satisfaction). As the term suggests, Quality of Life is typically considered a quality or characteristic of one's life and HRQL is an independently definable quality or state of one's life (or health). Although such perceptions are subjectively influenced by disease processes, they are thought to exist somewhat universally and independently of particular life events and circumstances.

On the surface, measures of patient satisfaction may appear to be just another type of HRQL or Health Status measure. Indeed, both HRQL and satisfaction constructs are both strongly influenced by the effects of illness and moderated by the effects of available treatments. Nevertheless, these classes of PROs differ in some profound ways. A closer inspection reveals that satisfaction measures are actually composed of questions asking patients to make judgments or appraisals about a specific set of treatment-related events and experiences. Treatment/patient satisfaction may be thought of as an interaction between a set of personal expectations and judgments and particular experiences associated with current or past treatments. HRQL and Health Status, on the other hand, are appraisals of a quality or status of one's health, and thought to exist somewhat independently of specific situational events.

Such a distinction between the two types of measures is more clearly appreciated when one realizes that HRQL measures may be used prior to starting a treatment at baseline but that the same cannot be said for treatment satisfaction. Prior to the occurrence of a treatment event, one cannot assess treatment satisfaction only the expectations or anticipations towards future treatment events. Moreover, such expectations have been shown to be relatively weak predictors of patients' later satisfaction with treatment [59]. Thus treatment satisfaction can be thought of as an experiential appraisal of the degree to which a current treatment has been able to moderate the impact of illness without being causing bothersome side effects or be a great inconvenience. Such a distinction may explain why measures of treatment satisfaction do not seem to be as strongly associated with patients' emotional states as HRQL measures [60].

Thus satisfaction and HRQL/Health Status measures focus on different, although interrelated, PRO constructs. Any decision to use one as a proxy for another would be based on a fair number of assumptions that are not yet well understood. The use of HRQL/Health Status measures as a proxy for evaluation of patient need may be more easily justified. A parallel can be drawn between 'patient need' as defined by the authors of this author, namely, a state of

discrepancy from a condition that most healthy persons would be expected to possess. **Mark J. Atkinson**

Quality of life is only a moderate proxy of satisfaction with care as the latter, but not the former, is strongly dependent of the \*process\* of care, and not just its outcome. Patients who experienced an important improvement in quality of life are likely to be more satisfied than those who do not; however, a patient who responds dramatically to a treatment may have poor satisfaction if, for example, the clinician was rude, treatment overly expensive or waiting times too long. Quality of life, satisfaction and needs are distinct concepts that should largely be measured separately; that said, it is not always important to measure all three. **Andrew Vickers**

This question cannot be addressed without a clear conceptual model linking medical care to physiological and psychological health to quality of life and satisfaction [61]. Quality of life is not a proxy for satisfaction unless measured using scales that incorporate patients' own utilities. **Richard Kravitz**

I really appreciate the discussion you approached in this paper. Several years ago, physicians tried to treat a disease, supposing that a reduction in the tumoural mass could improve patients' health status. In this context, complete or partial responses by the tumour were classified as "response rate", and the response rate was considered as the main outcome of a treatment.

Unfortunately, it was easy to demonstrate that response rate and overall survival were not always correlated; response rate was classified as an index of activity and overall survival as an index of efficacy of a treatment, using response rate as a surrogate index of efficacy in clinical practice.

Likewise, after the first enthusiastic results of chemotherapy against metastatic tumours, a plateau in the outcomes was rapidly reached, and all oncologists met a sort of stalemate in the results of their approaches, regardless the introductions of new molecules or new schedules. It was the time when the oncologists became aware of the side effects of chemotherapy, and beyond side effects, the way to overcome the resistance to chemotherapy and to outcome improvement were considered.

Unfortunately, neither the CSF, nor the other cytoprotectants favoured a significant improve in the outcomes of treatment of the most part of solid tumours, although it was evident that chemotherapy could be better tolerated with the use of appropriate supportive approaches.

When it became evident that an improve in overall survival could not be so easy to obtain with standard chemotherapy in a large part of solid tumours, the oncologists reconsidered the problem of the symptoms burden, hypothesising both a possible role of chemotherapy in the treatment of cancer-related symptoms, and a direct relationship between response rate and symptoms improve. Two approaches were followed:

- The identification of arbitrary indices to define and assess the clinical benefit in cancer-related symptoms with chemotherapy;
- The identification of a new field for clinical research, in which quality of life (or better "health-related quality of life") was defined as an outcome for a medical approach.

Introducing health-related quality of life raised further problems:

- What was the relationship between health-related quality of life and overall survival (if any)?
- What was the relationship between symptom relief and quality of life (if any)?
- Did health-related quality of life represent an outcome both in patient's and physician's points of view?

In this context this paper about patients' needs, satisfaction and quality of life intervenes approaching some controversial aspects of the problem:

- Are the researches in quality of life, patients' needs or satisfaction adequately approached in clinical setting? In my opinion the response is no, as we are still creating in our mind a surrogate index of the needs of patients that is still too much "physician-related" but too-little "patient-related".
- Can improvement in health-related quality of life be assumed as an index of satisfaction of the patient? In my opinion the response is no, because it only represents the "health-related" dimension of quality of life, that could be strictly related to, but shall not be considered the same of patient satisfaction.
- Are we sure that we have all the instruments to assess the needs and satisfaction of our patients? I do not know, but I fear for two potential risks that we will be contented with the easiest solution of some surrogate composite indices of satisfaction (as occurred with clinical benefit and quality of life in clinical oncology) avoiding to define better instruments to assess needs and satisfaction, or, worse, that the needs and satisfaction assessment (or their surro-

gate indices) will be used as an instrument for a political or administrative consent, that is so far from- (but unfortunately even so near to-) the real dimension of patients. **Davide Tassinari**

The use of the word proxy is in my opinion inappropriate: Quality of life, (QoL) Health Care Needs (HCN) and Satisfaction (Sat) are all distinct concepts and QoL cannot be assessed "in the place of" the other two. An attempt to prove this replaceability was made by measuring the correlation between them [3] the absence of such correlation would be surprising!!

A sound proof would have been to demonstrate that the contents of the three concepts are equivalent, but, unfortunately, this is not true also when speaking of different instruments for quality of life evaluation and is very likely to be false for the three concepts in examination. Identifying quality of life score cut-offs able to detect high levels of HCNs or low levels of Sat at an appreciable degree of sensitivity and specificity would be useful but would not solve the problem to have valid and reliable instruments for HCNs and Sat assessment. **Cinzia Brunelli**

Views will vary. However if we assume the needs of patients represent their judgement about whether or not they wish to receive assistance with a particular area, reflected an item on questionnaire, then quality-of-life should not be used as a proxy. For example patients suffering from chronic condition may experience a substantive pain, not be able to take care of themselves and lack of mobility. For most quality-of-life scales this would be reflected in a low score. A poor quality-of-life. This maybe an accurate representation of the respondents experience. However, perceived needs may reflect what the respondent may wish to have improved. That is, they may indicate while that they are experiencing considerable pain is not that that they wish assistance with but how to deal more effectively with the medical system or get help for their partner. Given this scenario it is clear that quality-of-life should not be used as a surrogate measure for perceived needs. **Rob Sanson-Fisher**

This is a question that must be responded with empirical evidence. In my opinion, there is a likely relationship between the concepts, but the direction and strength of this association must be ascertained in practice. **Luis Prieto**

In my recent article [62] I distinguish between satisfaction with medication, treatment satisfaction, and satisfaction with health delivery. In the article cited above, I point out that HRQL needs to be distinguished from satisfaction with medication; the former basically represents the status of a patient on dimensions assumed to of importance,

whereas satisfaction is evaluative in nature. Therefore, I do not think that HRQL can be used as a proxy for satisfaction. **Richard Shikiar**

These are testable hypotheses on which research should be encouraged. However, as we anxiously await the results of the research we should never forget the words of the philosopher George Santayana, "Those who do not learn from history are doomed to repeat it". **Chris Haffer**

#### **What is the evidence for psychometric properties of the instruments used to evaluate satisfaction and needs?**

Regarding satisfaction, the single biggest problem across virtually all of them is a ceiling effect. We can at least take heart in knowing that most people report being very satisfied with their care. Regarding needs, this area has seldom moved beyond the qualitative level, reporting proportions of people having the studied range of needs. One example of a needs-based (or, more accurately, rehabilitation-based) instrument in oncology, is the Cancer Rehabilitation Evaluation System (CARES). **David Cella**

Well, for the latter, it's there in the literature – from Rosser and watts on, through Torrance and the army of QALY, HYE etc. measurers. As for satisfaction, there's a huge economic and psychological literature but there's a lot of mystery as to what 'satisfaction' means. Many take it – wrongly – as a synonym for 'utility' – though not, I think, most utilitarians. **Anthony Culyer**

I can not give you a conclusion regarding the psychometrics of satisfaction outcomes in orthopaedics. However, psychometric data on satisfaction measures in total joint replacement have been reported [63]. **Ewa Roos**

Standards with which to judge the psychometric properties of various types of PRO measurement tools have been clearly established for several decades [64] and continue to be refined [65,66]. All PROs should be held to the same high standards of both classical and modern measurement theory, and be shown to possess adequate reliability, validity, and responsiveness to the phenomenon in question.

What is needed in our field is to sharpen the ways in which we conceive of our PRO constructs [67] and to elucidate the inter-relationships between direct and mediated causal pathways between such constructs and illness or treatment conditions [2,68]. Too often conceptual distinctness between outcome measures is blurred. This is clearly evident when instrument content (e.g., appraisals of medication effectiveness or ratings of disease severity) are indiscriminately mixed together with temporally distinct constructs in the causal pathway (e.g., the behavioral ramifications of the appraisal). For example, mixing treat-

ment experience questions with one addressing the "willingness to recommend to a friend" or, in the case of disease severity ratings, the functional effects of symptom severity on daily activities. The lack of conceptually coherent measures precludes elaboration of conceptual frameworks with which to understand our empirical observations.

As acknowledged in the preceding article, while Quality of Life is broadly conceptualized, it is most often more narrowly operationalized by disease-specific HRQL measures. Similarly, patient satisfaction can be broadly thought to refer to all relevant experiences and processes associated with a healthcare delivery, while treatment satisfaction typically focuses on events related to a particular medication or surgical treatment. When designing new PRO tools, the referential scope of our measures is an important consideration. General and specific measures yield different sorts of information and perform in differing ways. Narrowly specified PROs tend to be more useful when the objective is to gain context specific understanding within a particular disease state. Moreover, such measures also tend to be more responsive to changes in the underlying cause(s) over time (e.g., disease severity or treatment effects). On the other hand, more broadly defined PROs are generally phrased and, because of this they allow for greater diversity in how respondents interpret their meaning. Such instruments allow for comparisons of diverse patient populations but provide more limited insight into the underlying reasons for observed differences. **Mark J. Atkinson**

There has been progress. In the recent past, satisfaction surveys were performed without any information on the psychometric properties of questionnaires. At present, information on the validity of these questionnaires is collected. The criterion validity (degree to which the questionnaire measures the true situation) and responsiveness of these questionnaires is hard to assess. In many research on patient satisfaction in the oncology field, it appears that patients are less satisfied with the information provided compared to other aspects of care. This should lead to prioritise initiatives to improve information provision at the expense of other care aspects improvement. I think that further research need to be performed to understand the meaning of these results. **Anne Brédart**

Developers of instruments designed to measure patient satisfaction face a paradox. On the one hand, mean scores are invariably high (i.e., there is a ceiling effect). On the other hand, huge numbers of patients every year switch doctors and health plans, do not comply with recommended therapy, sue their doctors (or at least think about it), and complain to their children about their medical care. We may need to acknowledge that we are bumping

up against a "wall of cognitive dissonance" that creates a theoretical limit to the value of satisfaction ratings.

Another important and unresolved issue is whether to adjust for patient characteristics when comparing satisfaction ratings among providers. It is well known that age, ethnicity, and health status (among other characteristics) influence patients' ratings of satisfaction. Some organizations have decided to use raw (unadjusted) comparisons based on the argument that health care organizations and practitioners need to adapt to their own patient populations and provide whatever is needed to generate satisfaction in the groups they serve. But this may be a little unfair. In our own primary care clinic at UC Davis, Russian-speaking patients almost *never* choose the (properly translated) "excellent" column when rating their care, while Spanish-speaking patients use it liberally. Physicians who see many Russian-speaking patients (or other groups with systematically higher thresholds for satisfaction) have a right to be concerned. **Richard Kravitz**

Traditionally the determination what constitutes an adequate measure has been grounded in the psychometric literature. There is some reason to continue the utilisation of concepts such as test retest reliability, face and content validity. Concurrent validity has appeal when similar measures exist but is heavily dependent on the concept that the existing measures accurately betray the issue under consideration. To compare a new measure against an existing inappropriate or an accurate measure is obviously foolhardy and inappropriate. The use of confirmatory factor analysis appears dubious as strategy for examining the potential usefulness of the scale. The fact that the items may be statistically related and then delete other items may mean that the most predictive items are discarded. More importantly it is whether the scale can predict future behaviour, use of resources or outcomes such as mortality or morbidity. It is unusual for the development of new scale to be asked to demonstrate its predictive validity and more difficult to achieve this important goal. It may be timely for those involved in the construction of questionnaires to consider some of the dimensions used by epidemiologists when discussing the robustness of a new testing procedure. **Rob Sanson-Fisher**

A simple search of the literature shows that there is an emerging emphasis in assessing the psychometric properties of this type of instruments. In any case, I would like to challenge the audience of this editorial with more open questions: Is the 'need' attribute really quantitative? Does it deserve the application of psychometric methods directed to assign a number to the amount of 'need' that a given patient has? Or the 'need' is it just a dichotomous variable (i.e. need present/need absent) that should not

be defined by the patient itself but by professional health care agents? **Luis Prieto**

Through its leadership in standardizing satisfaction instruments and publicly reporting the results, the U.S. Agency for Healthcare Research and Quality, and the U.S. Centers for Medicare and Medicaid Services has sponsored research on many aspects of measuring satisfaction including psychometric properties of the instruments. A good place to begin a review of the relevant literature is: <http://www.cahps-sun.org/References/References.asp#sart>. **Chris Haffer**

**Have studies of patients' satisfaction been conducted but not published because of negative results, poor validity, reliability and responsiveness of the instruments developed (i.e. a high levels of ceiling effect towards high level of satisfaction due to patients fear of giving negative evaluations)? Or studies which could not be published because non-validated instruments were deployed, to assess patient satisfaction, not only wasting scarce hospital resources but also delaying changes in health service delivery by local health authorities**

It's not clear to me that there has been such a publication bias with regard to satisfaction studies. But to the extent this is true, I don't have the impression it is any more a problem with satisfaction studies as opposed to others, except for the ceiling effect issue. The problem people tend to face with satisfaction studies or outcomes, is that because most patients already have a high degree of satisfaction, it may be difficult to improve it further when it comes to treatments that affect patient quality of life. Hospitals in the US can tend to focus on patient conveniences and impressions such as parking, lobby feel, way-finding and personal services to improve satisfaction ratings, leaving actual care delivery in the hands of the providers. **David Cella**

Isn't the premise of this question false? **Anthony Culyer**

Various problems face those wishing to further our understanding of patient satisfaction. The most important seems to be a lack of good psychosocial science in the field, which may in-part be due to a resource-strained healthcare system. At the risk sounding somewhat repetitive; conceptually, Patient Satisfaction, Satisfaction with Care, and Treatment Satisfaction should be clearly distinguished from each other both on their scope measurement (i.e., level of generality-specificity) and on their context of measurement (e.g., satisfaction with healthcare, care provided by providers, characteristics of treatment etc.) Without a sound conceptual basis measures will lack coherence, produce uninterpretable or ambiguous results, and consequently be unable to benefit current organizational or business processes. This may be why many satis-

faction studies are one-off, and not adopted as a routine assessment of clinical care. Also impeding substantive advancements are a host of poorly designed and inadequately tested measures, which are often applied using very weak study designs. These factors make it very difficult to increase the credibility of such evaluation activities through publication in reputable peer-reviewed journals. **Mark J. Atkinson**

Our measures of patient outcomes and satisfaction are variegated and deeply flawed. Nevertheless, one of the most promising trends in health care today is the collection and sharing of information about patient outcomes and satisfaction at the hospital and medical group level. Unlike the uncoordinated efforts of the past, these initiatives seem to have roused health care executives from a deep slumber. Large measurement collaborations should be encouraged at the same time that we support more basic work on instrumentation. **Richard Kravitz**

There will always be cases where studies of patient satisfaction and other measures are not published because of their perceived lack of psychometric vigour. It is also the case that when one is attempting to change the health-care system by presenting findings which suggested adequate care is being provided to the patient group the professionals who are being asked to change will often resist using whatever strategies they can. One of the methods is to criticise the nature of the research or the research instrument. Consequently, it is reasonable that the instrument such as a patient satisfaction measure is credible. However, as suggested in my response to question for this may not necessarily mean the usual criteria that are used by psychometricians. **Rob Sanson-Fisher**

In the U.S. a number of studies on patients' satisfaction have been conducted and reported in the peer-reviewed literature. As noted above a good place to begin is: <http://www.cahps-sun.org/References/References.asp#sart>. **Chris Haffer**

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