

Quality of Life Literature Review Appendix

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Appendix A

Quality of life research

In this appendix we list studies that examined the relationship between quality-of-life measurement and conditions that could potentially result in eligibility for VA disability benefits. We draw on two bibliographies: one supplied to us by the Institute of Medicine and the other contained in the Australian Centre on Quality of Life website. We include the article abstract as well as the quality of life measure that is applied. Articles are grouped by condition into the following categories: chronic fatigue syndrome (5), mental non-PTSD (9), PTSD (8), diabetes (18), heart (13), breathing (13), back (6), arthritis (10), neurological (2), endocrine (2), visual (2), auditory (3), affect on family members (9), other (2), and veterans (11).

We provide a brief abstract of each individual source document. The abstracts were drawn heavily from the authors' own abstracts, when they were available. If authors' abstracts were not available, we summarized the relevant material from the citation.

Chronic fatigue syndrome (5)

[1] Fiedler, N., et al. "Stressors, personality traits, and coping of Gulf War Veterans with chronic fatigue." *Journal of Psychosomatic Research*, 2000, 525-537.

File:

QOLM CFS JPR.pdf

Measure

Complete physical, psychiatric, and neuropsychological evaluation

Abstract

Preliminary surveys of Persian Gulf veterans revealed a significant prevalence of self-reported symptoms consistent with chronic fatigue syndrome (CFS). The purpose of this study was to compare self-reported life stressors, combat, and chemical exposures, personality and coping between Gulf War veterans with CFS and healthy veterans. Following a complete physical, psychiatric, and neuropsychological evaluation, 45 healthy veterans, 35 veterans with CFS and co-morbid psychiatric disorder, and 23 veterans with CFS and no co-morbid psychiatric disorder completed questionnaires assessing war and non-war-related life stressors, self-reports of environmental exposure (e.g. oil well fires, pesticides), personality, and coping. The authors found that measures of personality, self-reported combat and chemical exposures, and negative coping strategies significantly differentiated healthy veterans from those with CFS. The study concludes that a biopsychosocial model of veterans' illness was supported by the fact that personality, negative coping strategies, life stress after the war, and environmental exposures during the war were significant predictors of veterans' current physical function.

[2] Anderson JS and CE Ferrans. "The quality of life of persons with chronic fatigue syndrome." *J Nerv Ment Dis* 1997; 185: 359-67.

File:

QOLM CFS 97.htm

Measure

QOL index supplemented by interviews

Abstract

This descriptive study used a between-methods triangulation design to analyze the multiple dimensions of quality of life in persons with chronic fatigue syndrome (CFS). This method, which refers to the combination of both quantitative and qualitative methods in the same study, allowed the authors to obtain more comprehensive and robust data than could be obtained by either method alone. A con-

venience sample of 110 persons with CFS completed the quality of life index and CFS questionnaire, and a subset of 22 persons were interviewed regarding their lived experience with CFS. Overall scores on the quality of life index were significantly lower in CFS than for other chronic illness groups. Subjects reported the lowest quality of life scores in the health and functioning domain. In-depth interviews provided a more complete understanding of the quality of life in CFS and further explained the low ratings that were found on the quality of life index. The findings suggest that quality of life is particularly and uniquely disrupted in CFS.

[3] Hardt, J., et al. “Health-related quality of life in patients with chronic fatigue syndrome: An international study.” *J Psychosom Res* 2001; 51:431-4.

File

QOLM CFS Hardt 2001.pdf

Measure

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

Chronic fatigue syndrome (CFS) has been reported worldwide. Our objectives were to determine if patients from different countries have similar profiles of impairments. Health-related quality of life (HRQoL) was assessed in 740 CFS patients in the US, 82 in the UK, and 65 in Germany using the eight subscales of the Short-Form General Health Survey (SF-36). To examine the internal structure, factor analyses were performed. Overall, there was a remarkable similarity in HRQoL among all CFS patients, regardless of location. Patients scored two to three standard deviations below normal on six subscales and one standard deviation below normal on the other two subscales. Factor analysis suggested a two-factor model where the same six subscales constitute the first factor and the two others the second factor. The authors concluded that HRQoL is poor in CFS patients from three countries. This study is a first step towards

conducting further comparative cross-cultural and international studies.

[4] Myers, C. and D. Wilks. "Comparison of Euroqol EQ-5D and SF-36 in patients with chronic fatigue syndrome." *Qual Life Res* 1999; 8: 9-16.

File

QOLM CFS 99.pdf

Measures

Euroqol EQ-5D (Euroqol) and Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The objective of the study was to compare the Euroqol EQ-5D (Euroqol) and short-form 36 (SF-36) health questionnaires in patients with chronic fatigue syndrome (CFS). One hundred and twenty-seven outpatients referred to a hospital-based infectious disease clinic with a diagnosis of CFS were contacted by post and asked to complete both questionnaires. Additional data were determined from hospital case notes. Eighty-five patients returned correctly completed questionnaires.

Euroqol health values and visual analogue scale (VAS) scores were strongly and significantly correlated with all dimensions of the SF-36, with the exception of physical limitation of role. SF-36 dimensions were in turn strongly and significantly correlated with each other, with the same exception. Patients reported a high degree of physical disability and a moderate degree of emotional or psychological ill-health. The Euroqol elements dealing with mobility and self-care referred to inappropriately severe degrees of disability for these patients with CFS. Similarly some dimensions in the SF-36 were oversensitive and did not discriminate between patients with moderate or severe disability.

It was concluded that Euroqol scores correlated strongly with SF-36 scores and provided useful information about patients with CFS and

that Euroqol would be a useful tool for the rapid assessment of health status in CFS. The current Euroqol instrument refers to inappropriately severe degrees of disability for patients with CFS and would need to be modified to be maximally useful in this situation.

[5] Schweitzer, R., et al. 1995. "Quality of Life in Chronic Fatigue Syndrome." *Social Science Medicine*, 41(10):1367-1372.

File

QOL CFS 95.pdf

Measure

The Sickness Impact Profile (SIP)

Abstract:

Whilst the debilitating fatigue experienced in patients suffering from Chronic Fatigue Syndrome (CFS) results in a subjective marked impairment in functioning, little research has investigated the impact of this disorder on quality of life. Forty-seven subjects with a confirmed diagnosis of CFS and 30 healthy controls were compared using the Sickness Impact Profile (SIP). A subgroup of subjects were interviewed regarding the impact CFS has had on their social and family relationships, work and recreational activities. Results from both the SIP and the interview revealed that CFS subjects had significantly impaired quality of life, especially in areas of social functioning. These findings highlight the importance of addressing the social isolation and loss of role functioning experienced by CFS sufferers.

Mental non PTSD (9)

[1] Beng-Choon, H., et al. "Two-year outcome in first-episode schizophrenia: Predictive value of symptoms for quality of life." *American Journal of Psychiatry*, 1998, 155:1196-1201.

File

QOLM Ment 1998.pdf

Measures

QOL at 2-year follow-up.

Abstract

Many studies have validated the grouping of schizophrenic symptoms into three independent dimensions: negative, psychotic, and disorganized. Negative symptoms are considered to be an important prognostic indicator, but this clinical observation requires further empirical study, especially with respect to psychosocial functioning. When present at the onset of the first episode, negative symptoms suggest that the patient will develop significant psychosocial impairment. The predictive values of the psychotic and disorganized symptom dimensions, on the other hand, have been less certain.

In this study of 50 first-episode schizophrenic patients, who were mostly neuroleptic-naive at intake, the authors examined the relationship between the severity of these three symptom dimensions (measured by using the Scale for the Assessment of Negative Symptoms and the Scale for the Assessment of Positive Symptoms) at index hospitalization and quality of life at 2-year follow-up.

Negative symptom severity was positively and significantly correlated with later occupational impairment, financial dependence on others, impaired relationships with friends, impaired ability to enjoy recreational activities, and global assessment of functioning. The magnitudes of correlation between the levels of psychotic symptoms or disorganized symptoms and 2-year quality of life measures were comparatively lower. Analyses using multivariate regression statistics also revealed similar findings.

Severity of negative symptoms at index hospitalization may be a portent of poor outcome. In general, severity of psychotic or disorganized symptoms at intake does not appear to predict subsequent quality of life.

[2] Strine, Tara W., et al. "Depression, Anxiety, and Physical Impairments and Quality of Life in the U.S. Noninstitutionalized Population." *Psychiatric services*, December 2004 Vol. 55 No. 12.

File

QOLM Ment 2004.pdf

Measure

Behavioral Risk Factor Surveillance System

Abstract

The objective of this study was to examine health-related quality of life and health behaviors among persons reporting a primary mental health impairment compared with those reporting a primary physical health impairment and those reporting no impairment.

Data were obtained from the Behavioral Risk Factor Surveillance System, an ongoing state-based, random-digit telephone survey of the non-institutionalized U.S. population aged 18 years or older. In 2001-2002, health-related quality-of-life measures were administered in 23 states and the District of Columbia.

An estimated 5.1 percent of U.S. adults reporting a primary health impairment indicated that a mental health problem was the primary cause. Those with a primary mental health impairment were more likely than those with a primary physical health impairment to report infrequent vitality (less than 14 days in the previous 30 days) and frequent occurrences of mental distress, depressive symptoms, and anxiety (at least 14 days in the previous 30 days). Relative to those who reported no impairment, persons who reported a mental health impairment were more likely to indicate that they experienced frequent physical distress and frequent pain. Persons with a primary mental health impairment were more likely than those with a primary physical health impairment to smoke and drink heavily. No significant difference was found in self-reported frequent sleeplessness or fair-to-poor general health between persons with a primary mental health impairment and those with a physical health impairment.

Mental health impairment is strongly associated with reduced health-related quality of life and health behaviors, frequently at levels equal to or exceeding those of physical health impairments.

[3] Gaynes, BN, et al. "Depression and Health-Related Quality of Life." *J Nerv Ment Dis.* 2002 Dec;190(12):799-806.

File

QOLM Ment 2002.pdf

Measure

Epidemiological Follow-Up Study (NHEFS) of the first National Health and Nutrition Examination Survey (NHANES I)

Abstract

Chronic medical conditions drastically affect the lives of those afflicted, leading to pain, disability, and disruption. Comorbid depression can exacerbate the effects of medical illness and may be an independent source of suffering and disability. Data from the Epidemiological Follow-Up Study (NHEFS) of the first National Health and Nutrition Examination Survey (NHANES I) are used to examine the manner in which depression and comorbid medical conditions interact to affect health-related quality of life (HRQOL). The findings suggest a) that the effects of depression are comparable with those of arthritis, diabetes, and hypertension; and b) that depression and chronic medical illnesses interact to amplify the effects of the medical illness. The data also support the merit of adopting a multidimensional approach to HRQOL rather than treating it unidimensionally.

[4] Hollifield, M., et al. "Panic Disorder and Quality of Life: Variables Predictive of Functional Impairment." *Am J Psychiatry,* 1997 154(6):766-772.

File

QOLM Ment 97.pdf

Measure

Three measures from the Medical Outcomes Study Short Form 36-items Health Survey (SF-36) (general health perception, mental health, and physical functioning).

Abstract

The authors sought to characterize the functional impairment in patients with panic disorder, specifically the variance in impairment explained by demographic and clinical variables. Sixty-two patients with panic disorder and 61 comparison subjects from three primary care clinic sites were assessed with an adapted form of the Structured Clinical Interview for DSM-III-R. Impairment was assessed according to three measures from the 36-item Short-Form Health Survey (general health perception, mental health, and physical functioning) as well as a principal component factor of the survey. Subjects were also compared with respect to personality variables, presence and severity of chronic medical illness, and demographic characteristics. Stepwise multiple regressions with and without pairwise interactions were used to construct models of disability in the patients with panic disorder.

The patients with panic disorder were more impaired than comparison subjects on each measure of the Short-Form Health Survey. The panic disorder diagnosis combined with major depression, increasing neuroticism and age, less education, and an interaction between panic disorder and age accounted for 48 -77 percent of the variance in impairment scores. Gender and ethnicity contributed modestly to the variance in impairment in physical functioning, whereas no contribution was demonstrated for chronic medical illness or city of residence.

Factors in addition to panic phenomena contribute to the severe impairment seen in patients with panic disorder. Further research about factors that affect impairment may help improve clinical approaches to this illness.

[5] Lasalvia, A., et al. “Subjective quality of life: its relationship with clinician-rated and patient-rated psychopathology. The South-Verona Outcome Project 6.” *Psychotherapy and Psychosomatics*, 2002, 71(5), 275 -284.

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Not Available

Measure

Brief Psychiatric Rating Scale and the revised version of the Symptom Checklist 90, Lancashire Quality of Life Profile)

Abstract

This study compared clinician-rated and patient-rated psychopathology and analyzed their relationship with subjective quality of life (QoL) in a sample of patients with a wide range of psychiatric conditions attending a community-based mental health service. In the context of the South-Verona Outcome Project (SVOP), 139 patients were assessed for both clinician-rated and self-rated psychopathology (by using respectively the Brief Psychiatric Rating Scale and the revised version of the Symptom Checklist 90), and asked to report on their subjective quality of life (by using the Lancashire Quality of Life Profile). In order to explore the associations between psychopathology and subjective QoL bivariate and multivariate analyses were performed.

BPRS and SCL-90-R were poorly correlated, both in their total scores and in their various dimension scores. BPRS showed only a modest negative correlation with LQL, which, in contrast, was highly negatively correlated with SCL-90-R. Regression analyses showed that patient-rated psychopathology was the strongest predictor of subjective quality of life, with self-rated depressive symptoms and self-reported paranoid ideation having the highest predictive power.

Self-reported psychological distress is more important than clinician-rated symptom severity in predicting subjective QoL. In order

to improve QoL, psychiatric treatment should focus not only on simple reduction of symptoms but also on patients' subjective psychological distress.

[6] Lehman, AF. "Measures of Quality of Life among Persons with Severe and Persistent Mental Disorders." *Social Psychiatry and Psychiatric Epidemiology*, 1996 31:78-88.

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Measure

Literature review

Abstract

In order to provide clinicians, researchers, program evaluators, and administrators with current information on the assessment of humanistic outcomes of services for persons with severe and persistent mental illnesses (SPMI), the literature on measuring quality of life (QOL) for these persons is summarized. The literature on QOL assessment procedures up to the end of October 1992 for persons with SPMI is reviewed, covering QOL measures that at a minimum assess subjective well-being. Measures are summarized according to purpose, content, psychometric properties, patient subgroups with whom used, and key references. Ten QOL measures are summarized and reflect considerable variability on the parameters examined. Comprehensive, reliable, and valid measures of QOL are available although further development of QOL assessment methodologies is needed. More importantly, the authors conclude we must strive for a better understanding of how to interpret and use QOL outcome information.

[7] Russo, J. et al. "Longitudinal assessment of quality of life in acute psychiatric inpatients: Reliability and validity." *The Journal of Nervous and Mental Disease*, 1997, 185(3):166-175.

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QOLM Ment 97.html

Measure

Lehman's Quality of Life Interview (QOLI)

Abstract

This study examined the reliability, validity, and responsiveness of Lehman's Quality of Life Interview (QOLI) as an outcome measure on 981 acutely ill psychiatric inpatients assessed longitudinally at admission and discharge. Patients were stratified into five diagnostic (DX) (depressed bipolar, depressed unipolar, schizophrenia, mania, and other diagnoses) and two substance use disorder (SA) strata (with and without concurrent substance abuse/dependence) based on DSM-III-R criteria. There was good replication of the factor structure, excellent internal consistency, overall and within DX and SA groups. Intercorrelations showed that the functional and satisfaction indices measure unique aspects of the quality of life.

The construct consistency of the QOLI was dependent upon psychiatric diagnosis and life domain. Intercorrelations of functional and satisfaction indices for patients with depression were greater than for manic patients. The authors demonstrated strong consistency of construct validity for family and social relation domains, but not safety or leisure activities. Construct validity was shown to hold longitudinally. Analyses of DX and SA group differences on satisfaction and functional indices of the 8 life domains supported discriminative validity: Depressed patients reported the most dissatisfaction, followed by schizophrenic patients, and manic patients reported the greatest satisfaction in most life domains. Patients with concurrent substance abuse generally reported less satisfaction and lower quality of life than patients without a dual diagnosis.

Examination of longitudinal changes in satisfaction indicated the QOLI is responsive to changes in global life, leisure activities, living situation, and social relations from hospital admission to discharge (an average of 2 weeks). This study supports the use of the QOLI as an outcome measure to assess quality of life in acutely ill hospitalized psychiatric patients.

[8] Schonfeld, WH., et al. "The functioning and well-being of patients with unrecognized anxiety disorders and major depressive disorder." *Journal of Affective Disorders*, 1997, 43:105-119.

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QOLM Ment Schon 97.pdf

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

This study examines the degree to which untreated anxiety disorders and major depressive disorder, occurring either singly or in combination, reduce functioning and well-being among primary care patients. Adult patients were screened using the SCL-52 to identify those with clinically significant anxiety symptoms. They also completed the Rand Short-Form (SF-36) to measure self-reported patient functioning and well-being. Patients with untreated disorders were identified using the Q-DIS-III-R to diagnose six DIS-anxiety disorders (generalized anxiety disorder, post-traumatic stress disorder (PTSD), simple phobia, social phobia, panic/agoraphobia, obsessive/compulsive disorder) and major depression.

Of 319 patients identified, 137 (43 percent) had a single disorder and 182 (57 percent) had multiple disorders. Regression models estimated the relative effects of these disorders on health status (SF-36) by comparing patients with the disorders to patients screened as being not-anxious. Estimates of these effects were consistent with available national norms. The estimated effect of each single disorder on all subscales for physical, social and emotional functioning was negative, often as much as a 20-30 point reduction on this 100-point scale. Major depression had the greatest negative impact, followed by PTSD and panic/ agoraphobia. For patients with multiple disorders, the presence of major depression was associated with the greatest reduction in functioning status. The impact of untreated anxiety disorders and major depressive disorder on functioning was

comparable to, or greater than, the effects of medical conditions such as low back pain, arthritis, diabetes and heart disease.

[9] Alonso, J., et. al. "Disability and quality of life impact of mental disorders in Europe: results from the European Study of the Epidemiology of Mental Health Disorders (ESEMeD) project." *Acta Psychiatrica Scandinavica*, 2004, 109 (420), 38-46.

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QOLM Ment Alonso 2004.pdf

Measures

Work loss days (WLD) in the past month and quality of life (QoL) were assessed, using the WMH-2000 version of the CIDI, the WHODAS-II, and the mental and physical component scores (MCS, PCS) of the 12-item short form)

Abstract

This manuscript examines the impact of mental health state and specific mental and physical disorders on work role disability and quality of life in six European countries. The ESEMeD study was conducted in: Belgium, France, Germany, Italy, the Netherlands and Spain. Individuals aged 18 years and over who were not institutionalized were eligible for an in-home computer-assisted interview. Common mental disorders, work loss days (WLD) in the past month and quality of life (QoL) were assessed, using the WMH-2000 version of the CIDI, the WHODAS-II, and the mental and physical component scores (MCS, PCS) of the 12-item short form, respectively. The presence of five chronic physical disorders: arthritis, heart disease, lung disease, diabetes and neurological disease was also assessed. Multivariate regression techniques were used to identify the independent association of mental and physical disorders while controlling for gender, age and country.

In each country, WLD and loss of QoL increased with the number of disorders. Most mental disorders had approximately 1.0 SD-unit lower mean MCS and lost three to four times more work days, compared with people without any 12-month mental disorder. The 10 disorders with the highest independent impact on WLD were: neu-

rological disease, panic disorder, PTSD, major depressive episode, dysthymia, specific phobia, social phobia, arthritis, agoraphobia and heart disease. The impact of mental verses physical disorders on QoL was specific, with mental disorders impacting more on MCS and physical disorders more on PCS. Compared to physical disorders, mental disorders had generally stronger 'cross-domain' effects.

The results suggest that mental disorders are important determinants of work role disability and quality of life, often outnumbering the impact of common chronic physical disorders.

Post Traumatic Stress Disorder (8)

[1] Dekel, R., et al. "The contribution of social disability to the evaluation of mental disability among PTSD Veterans." *Israel Journal of Psychiatry and Related Sciences*, 2005, 41(4), 237-247.

File

Not available

Measure

Social function

Abstract

Israeli veterans who claim for recognition of their mental disability and compensation undergo multi-professional assessments including a detailed psychosocial evaluation. To conduct a systematic evaluation of the social disabilities of veterans with PTSD; to examine the relationships between the various aspects of their social disability and their PTSD symptom severity, on the one hand, and the ratings they receive from psychiatrists determining their overall disability, on the other hand.

The study was conducted on 120 veterans with PTSD, all filing for compensation. Data was collected by means of semi-structured interviews that were carried out by social workers in a joint meeting with the veterans and their spouses and that covered marital, parental and social functioning; from the self-report PTSD questionnaire

that the veterans filled out; and from the final disability ratings in the veterans' files.

Findings showed a disturbing picture of impaired marital, parental and social functioning of veterans with PTSD. In addition, they indicate that both PTSD severity and the psychiatrists' disability ratings were correlated with only a quarter or so of the veterans' specific social disabilities in the areas studied. Several explanations for the pattern of correlations between these two assessments are offered. In addition, the authors highlight the importance of a sensitive and detailed evaluation of social disability as well as recommending the development of practical guidelines for the determination of disability.

[2] Zatzick, D.F., et al. "Posttraumatic Stress Disorder and functioning and quality of life outcomes in a nationally representative sample of male Vietnam veterans." *Am J Psychiatry*, 1997, 154(12), 1690-1695.

File

QOLM PTSD 97.pdf

Measure

Functional and quality of life

Abstract

Although posttraumatic stress disorder (PTSD) is a highly prevalent and often chronic condition, the relationship between PTSD and functioning and quality of life remains incompletely understood. The authors undertook an archival analysis of data from the National Vietnam Veterans Readjustment Study. The study subjects consisted of the nationally representative sample of male Vietnam veterans who participated in the National Vietnam Veterans Readjustment Study. The authors estimated PTSD at the time of the interview with the Mississippi Scale for Combat-Related Posttraumatic Stress Disorder. They examined the following outcomes: diminished well-being, physical limitations, bed day in the past 2 weeks, compromised physical health status, currently not working, and perpetration of violence.

Logistic models were used to determine the association between PTSD and outcome; adjustment was made for demographic characteristics and comorbid psychiatric and other medical conditions. Results: The risks of poorer outcome were significantly higher in subjects with PTSD than in subjects without PTSD in five of the six domains. For the outcome domains of physical limitations, not working, compromised physical health, and diminished well-being, these significantly higher risks persisted even in the most conservative logistic models that removed the shared effects of comorbid psychiatric and other medical disorders.

The suffering associated with combat related-PTSD extends beyond the signs and symptoms of the disorder to broader areas of functional and social morbidity. The significantly higher risk of impaired functioning and diminished quality of life uniquely attributable to PTSD suggests that PTSD may well be the core problem in this group of difficult to treat and multiply afflicted patients.

[3] Rapaport, M., et al. "Quality-of-Life Impairment in Depressive and Anxiety Disorders." *Am. J. Psychiatry*, 2005, 162:1171-1178.

File

QOLM PTSD 2005.pdf

Measure

Quality of Life Enjoyment and Satisfaction Questionnaire

Abstract

Previous reports demonstrating quality-of-life impairment in anxiety and affective disorders have relied upon epidemiological samples or relatively small clinical studies. Administration of the same quality-of-life scale, the Quality of Life Enjoyment and Satisfaction Questionnaire, to subjects entering multiple large-scale trials for depression and anxiety disorders allowed us to compare the impact of these disorders on quality of life. Baseline Quality of Life Enjoyment and Satisfaction Questionnaire, demographic, and clinical data from 11 treatment trials, including studies of major depressive disorder, chronic/double depression, dysthymic disorder, panic disorder, obsessive-compulsive disorder (OCD), social phobia, pre-

menstrual dysphoric disorder, and posttraumatic stress disorder (PTSD) were analyzed.

The proportion of patients with clinically severe impairment (two or more standard deviations below the community norm) in quality of life varied with different diagnoses: major depressive disorder (63 percent), chronic/double depression (85 percent), dysthymic disorder (56 percent), panic disorder (20 percent), OCD (26 percent), social phobia (21 percent), premenstrual dysphoric disorder (31 percent), and PTSD (59 percent). Regression analyses conducted for each disorder suggested that illness-specific symptom scales were significantly associated with baseline quality of life but explained only a small to modest proportion of the variance in Quality of Life Enjoyment and Satisfaction Questionnaire scores. Subjects with affective or anxiety disorders who enter clinical trials have significant quality-of-life impairment, although the degree of dysfunction varies. Diagnostic-specific symptom measures explained only a small proportion of the variance in quality of life, suggesting that an individual's perception of quality of life is an additional factor that should be part of a complete assessment.

[4] Arnold, L.M., et al. "Health-related quality of life using the SF-36 in patients with bipolar disorder compared with patients with chronic back pain and the general population." *Journal of Affective Disorders*, 2000, 57, 235-241.

File

QOLM Ment 2000.pdf

Measure

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The purpose of this study was to assess and compare the health-related quality of life of patients with bipolar disorder and chronic back pain and, in turn, to compare these results with those previously generated for the general population. Subjects were patients with bipolar disorder (n=44), a comparison group of chronic back

pain patients (n=30), and a population-based control sample (n=2,474). Health-related quality of life was assessed using the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36), a self-administered questionnaire in which lower scores are indicative of greater impairment.

Patients with bipolar disorder had lower mean scores than the general population on all scales except Physical Functioning. Bipolar patients had significantly higher scores than chronic back pain patients in the categories of Physical Functioning, Role Limitations - Physical, Bodily Pain, and Social Function. There were no significant differences between bipolar disorder and chronic back pain groups in the Mental Health and Role Limitations - Emotional categories. Limitations: The results of the study are limited by the relatively small sample sizes of the bipolar and back pain patient groups.

Patients with bipolar disorder had substantial impairment in health-related quality of life in comparison with the general population. Bipolar patients were less compromised in areas of physical and social functioning than chronic back pain patients but had similar impairment in mental health.

[5] Rapaport, M.H., et al. "Posttraumatic Stress Disorder and quality of life: Results across 64 weeks of sertraline treatment." *Journal of Clinical Psychiatry*, 2002, 63 (1), 59-65,

File

Not found

Measure

Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q), emotional role functioning and mental health subscales of the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36), as well as the occupational and social functioning items on the Clinician-Administered PTSD Scale, Part 2 (CAPS-2).

Abstract

The goal of the current study was to characterize the quality of life (QOL) and functional impairment associated with posttraumatic

stress disorder (PTSD) and to report the QOL/functional response over the course of long-term treatment. QOL and psychosocial functioning were analyzed in 359 randomly assigned patients across a 3-phase study of sertraline in the treatment of chronic DSM-III-R-defined PTSD: (1) 12 weeks of double-blind, placebo-controlled acute treatment with sertraline in flexible doses of 50 to 200 mg/day, (2) 24 weeks of open-label continuation treatment with sertraline among all study completers (regardless of initial study drug assignment or endpoint responder status), and (3) 28 weeks of double-blind, placebo-controlled maintenance treatment with sertraline in continuation phase responders. Assessments included the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q), emotional role functioning and mental health subscales of the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36), as well as the occupational and social functioning items on the Clinician-Administered PTSD Scale, Part 2 (CAPS-2).

At acute phase baseline, QOL was significantly impaired as reflected by a mean Q-LES-Q score of 56 percent of the total possible score and a CAPS-2 social/occupational impairment composite score of 4.4. Sertraline treatment was associated with marked improvement on all QOL/functional measurements: at the end of the acute treatment phase, 58 percent of responders on treatment with sertraline had achieved Q-LES-Q total scores within 10 percent of community norms. Twenty-four weeks of continuation treatment led to an additional 20 percent improvement in QOL and measures of functioning. Double-blind discontinuation of sertraline resulted in recurrence of PTSD symptoms and a worsening of QOL and functional measures, although the degree of exacerbation in symptomatology and psychosocial impairment was notably less than at study entry.

Sertraline treatment of chronic PTSD is associated with rapid improvement in quality of life that is progressive and sustained over the course of more than 1 year of treatment.

[6] Rosenheck, R.A., and A. Fontana. "Post-September 11 admission symptoms and treatment response among veterans with Posttraumatic Stress Disorder." *Psychiatric Services*, 2003, 54 (12), 1610-1617.

File

QOLM PTS 2003.pdf

Measures

Degree of pathology, were delineated: uncomplicated reactivation and heightened vulnerability

The authors conducted an exploratory study of the nature and course of reactivation of combat-related posttraumatic stress disorder. Experienced psychiatrists, they each independently assessed 35 men with recurrent combat-related posttraumatic stress disorder. Two major types of reactivated posttraumatic stress disorder, each representing a different degree of pathology, were delineated: uncomplicated reactivation and heightened vulnerability. The second category was further subdivided into specific sensitivity, moderate generalized sensitivity, and severe generalized sensitivity. The authors conclude that reactivation of war-related trauma is a complex phenomenon that may take different forms.

[7] Kapfhammer, H.P., et al. "Posttraumatic Stress Disorder and health-related quality of life in long-term survivors of acute respiratory distress syndrome." *American Journal of Psychiatry*, 2004, 161 (1), 45-52.

File

QOLM PTSD 2004.pdf

Measures

Dimensions of health-related quality of life

Abstract

Intensive care often means exposure to physical and psychological stress, with long-lasting emotional sequelae for most patients. Psy-

chiatric morbidity and negative effects on health-related quality of life were assessed in long-term survivors of acute respiratory distress syndrome. Forty-six long-term survivors were enrolled in a psychiatric follow-up study. All patients had received standard, protocol-driven treatment during intensive care. The median follow-up time was 8 years after treatment. DSM-IV was used for psychiatric diagnosis. Psychological tests were performed to measure posttraumatic stress symptoms; depression; state anxiety; somatization; symptoms regarding concentration, attention, and short-term memory; social support; and health-related quality of life.

At time of discharge, 20 of the patients suffered from posttraumatic stress disorder (PTSD) and four from sub-PTSD. At follow-up, 11 patients continued to suffer from PTSD and eight from sub-PTSD. The patients with PTSD demonstrated a pronounced tendency for somatization and state anxiety. Among the groups with PTSD, sub-PTSD, and no PTSD, there were no statistically significant differences regarding social support and symptoms of cognitive dysfunction. Those with PTSD showed major impairments in some dimensions of health-related quality of life, whereas those without PTSD had scores that were in the range of the general population. Except for duration of stay on the intensive care unit, neither age, gender, sociodemographic variables, premorbid psychopathology, nor initial severity of illness discriminated between the groups.

Long-term survivors of acute respiratory distress syndrome seem to face a major risk of PTSD and major impairments in health-related quality of life in the long term.

[8] d'Ardenne, N., et al. "Subjective quality of life and the Posttraumatic Stress Disorder." *Journal of Nervous and Mental Disease*, 2005, 193(1), 62-65.

File

QOLM PTSD 2000.pdf

Measures

Subjective quality of life (SQOL))

Abstract

Subjective quality of life (SQOL) and its predictors were assessed in 117 patients with posttraumatic stress disorder (PTSD) in a specialized clinic. Scores were compared with other samples. PTSD patients had lower SQOL than the comparison groups. Higher levels of depression and anxiety, fewer PTSD avoidance symptoms, being older, and being from an ethnic minority were all independent predictors of lower SQOL. The high dissatisfaction with several social domains of life should be considered in treatment, and depressive and anxiety symptoms might be targeted to improve SQOL.

Diabetes (18)

[1] Bergh, A.L., et al. "Psychometric properties of the Swedish version of the Well-Being Questionnaire in a sample of patients with diabetes type 1." *Scandinavian Journal of Public Health*, 2000, 28, 137-146.

File

QOLM Diab 2000.pdf

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The aim of the present investigation was to further test the psychometric properties of a Swedish version of the Well-Being Questionnaire (WBQ) in order to determine whether it could be suitable for measuring health-related quality of life among type 1 diabetic patients. In total, 94 patients who fulfilled the inclusion criteria were selected for the study and of these 85 percent participated. Reliability was tested with Cronbach's alpha coefficient and the internal validity by means of principal component analysis and multitrait analysis. To test the external validity, comparisons were made with two other questionnaires, the Short form-36 and a Swedish Mood Adjective Check List.

The results show that, above all, the Swedish version of the WBQ measures psychological well-being, and thus must also be complemented with scales that measure other consequences of the illness and/or treatment, i.e. physical symptoms. The questionnaire has low discriminatory validity between subscales, which casts doubt on the appropriateness of using the four subscales as separate measures. The two scales measuring anxiety and depression are not sensitive enough for use among type 1 diabetics without complications and high or normal levels of psychological well-being.

The Well-Being Questionnaire alone does not give any more information about subjective health status among type 1 diabetic patients than, for example, the generic SF-36.

[2] Hanestad, B. R., and G. Albrektsen. "The stability of quality of life experience in people with Type 1 diabetes over a period of a year." *Journal of Advanced Nursing* 1992, 17, 777-784

File

QOLM Diab 92.pdf

Measures

29 items measuring satisfaction in the physical, social, psychological and behavioral/activity life domains and 11 well-being scales)

Abstract

The aim of the present study was to examine the stability of self-reported quality of life experience over a period of 1 year using a standard measure consisting of 29 items measuring satisfaction in the physical, social, psychological and behavioral/activity life domains and 11 well-being scales. One hundred and six people with Type 1 diabetes attending a Norwegian diabetes clinic participated in the study. At first and second assessment, questionnaires were administered and completed at the diabetes clinic. Regression coefficients for the linear relationship between the assessments were relatively high indicating stability in reported quality of life experience over a period of 1 year. Comparisons between subjects experiencing life events relating to personal and/or family problems during the 12-month period and those not showed that, in addition

to stability coefficients being relatively high for both groups, the majority of the stability coefficients for the group reporting life events were not significantly different from the stability for the group reporting no life events.

[3] Rubin, Richard and Mark Peyrot. "Quality of Life and Diabetes, Diabetes/Metabolism Research And Reviews." *Diabetes Metab Res Rev*, 1999; 15: 205-218.

File

QOLM Diab 1999.pdf

Measures

English-language literature on self-perceived quality of life among adults with diabetes

Abstract

Quality of life is an important health outcome in its own right, representing the ultimate goal of all health interventions. This paper reviews the published, English-language literature on self-perceived quality of life among adults with diabetes. Quality of life is measured as physical and social functioning, and perceived physical and mental well-being. People with diabetes have a worse quality of life than people with no chronic illness, but a better quality of life than people with most other serious chronic diseases. Duration and type of diabetes are not consistently associated with quality of life. Intensive treatment does not impair quality of life, and having better glycemic control is associated with better quality of life. Complications of diabetes are the most important disease-specific determinant of quality of life.

Numerous demographic and psychosocial factors influence quality of life and should be controlled when comparing subgroups. Studies of clinical and educational interventions suggest that improving patients' health status and perceived ability to control their disease results in improved quality of life. Methodologically, it is important to use multidimensional assessments of quality of life, and to include both generic and disease-specific measures. Quality of life

measures should be used to guide and evaluate treatment interventions.

[4] Claiborne, N. and E. Massaro. "Mental quality of life: An indicator of unmet needs in patients with diabetes." *Social Work in Health Care*, 2000, 32, 25-45.

File

Not available

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

This exploratory study investigates the quality of life needs of 173 individuals being treated for type 2 diabetes over a six month period of time. It samples patients whose primary care providers practice the most current model for delivering care, diabetes disease management. These physicians utilized a multidisciplinary diabetes education program to facilitate the patient-provider knowledge-based partnership essential in disease management. Patient quality of life changes were measured by the SF-36. A paired samples t-test showed significant diminishment in patients' mental quality of life indicating diminished overall emotional functioning, negatively impacting quality of life; possibly due to the effects of time. Multiple regression results also indicated that patients at risk for major depression and at risk for major depression superimposed on dysthymia experienced significantly diminished mental quality of life. These findings suggest that enhanced mental health assessment and mental health services provided by social workers in diabetes education programs and/or primary care settings would improve patient mental quality of life.

[5] Snoek, F.J., et al. "Diabetes-related emotional distress in Dutch and U.S. Diabetic Patients." *Diabetes Care*, 2000, 23, 1305-1309.

File

Measures

Problem Areas in Diabetes Scale (PAID))

Abstract

The objective of the study was to examine the cross-cultural validity of the Problem Areas in Diabetes Scale (PAID) in Dutch and U.S. diabetic patients. A total of 1,472 Dutch people with diabetes completed the PAID along with other self-report measures of affect. Statistics covered Cronbach's alpha, exploratory factor analysis (EFA), and confirmatory factor analysis (CFA), Pearson's product-moment correlation, and t-tests. Psychometric properties of PAID were compared for Dutch and U.S. diabetic patients.

Internal consistency of the Dutch PAID was high and stable across sex and type of diabetes. Test-retest reliability was high. Principal component analyses confirmed 1 general 20-item factor, whereas EFA identified 4 new sub-dimensions: negative emotions, treatment problems, food-related problems, and lack of social support. These dimensions were confirmed with CFA and were replicated in the U.S. sample. The PAID and its subscales demonstrated moderate to high associations in the expected direction with other measures of affect. Dutch and U.S. subjects reported having the same problem areas, with U.S. patients reporting higher emotional distress levels both in type 1 and type 2 diabetes.

The Dutch and U.S. 20-item PAID appeared to be psychometrically equivalent, which allowed for cross-cultural comparisons. Psychological outcome measures of Well-being and Treatment Satisfaction have been designed and developed for people with tablet-treated Type 2 diabetes. The Well-being scale includes three six-item subscales to measure Depression, Anxiety, and Positive Well-being. A prime consideration when selecting items for the psychological well-being measures was to minimize the confounding of diabetic symptomatology with the somatic symptoms of depression and anxiety. Cronbach's alpha indicated that each of the Well-being subscales and the Treatment Satisfaction scale was internally reliable (alphas ranged from 0.70 to 0.88) and evidence for construct validity was

provided by predicted associations with other variables collected at the time of the study.

For example, lower Well-being scores were associated with being overweight (Depression: p less than 0.05; Anxiety: p less than 0.001) while greater Satisfaction with Treatment was associated with lower HbA1 levels (p less than 0.001) and lower percent ideal body weight (p less than 0.01). These scales should prove particularly useful where measures of quality of life are required to complement metabolic variables when evaluating new treatments, education programmes, and other interventions, or in the routine auditing of established methods of treatment.

[6] Bradley, C. and K.S. Lewis. "Measures of psychological well-being and treatment satisfaction developed from the responses of people with tablet-treated diabetes." *Diabetic Medicine*, 1990, 7, 445-451.

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Not available

Measures

QoL domains and sub-domains: social (daily, leisure, family and social life), psychological (emotional health and positive consequences), physical (physical health and treatment impact) and economic (employment and finances)

Abstract

The impact of lower extremity ulcers on the quality of life (QoL) of patients with diabetes and their caregivers was assessed in a series of focus groups. Fourteen patients with diabetes and lower extremity ulcers and 11 caregivers participated in the focus groups. Semi-structured discussions identified the issues relating to four broad QoL domains and sub-domains: social (daily, leisure, family and social life), psychological (emotional health and positive consequences), physical (physical health and treatment impact) and economic (employment and finances). The patients and care givers experienced a negative impact on all domains of QoL because of the limitations in mobility caused by the ulcer which required an

adaptation to a different lifestyle. Both groups experience a reduction in social activities, increased family tensions, lost time from work, and a negative impact on general health. It is necessary to separate the impact of the ulcer from the general condition of diabetes on both patients' and care givers' QoL.

The results from this disease-specific focus will allow for an improved clinical understanding with targeted interventions and contribute to the development of a disease-specific instrument to understand and measure QoL better in these individuals.

[7] Choe, M.A., et al. "Quality of life for patients with diabetes in Korea I: The meaning of health-related quality of life." *International Journal of Nursing Studies*, 2001, 38 (6), 673-682.

File

QOLM Diab Korea 2000.pdf

Measures

Open-ended interviews yielded six HRQOL themes: health, overall well-being, harmonious relationships and family responsibilities, a rewarding life, spiritual life, and material support

Abstract

This study describes the impact of diabetes and the meaning of health-related quality of life (HRQOL) for 22 male and female patients in Korea. Open-ended interviews yielded six HRQOL themes: health, overall well-being, harmonious relationships and family responsibilities, a rewarding life, spiritual life, and material support. The physical impact of diabetes included decreased energy, limitations, and physical suffering; while its psychological/spiritual impact extended to general stress, helplessness, fear, depression, anger, and relationship with God. Like Americans, Koreans valued health, psychological well-being and interpersonal support. In addition, the Koreans valued smooth, harmonious interpersonal relationships, overall well-being pertaining to living a comfortable and honorable life.

[8] Pouwer, F., et al. "The 12-item well-being questionnaire- An evaluation of its validity and reliability in Dutch people with diabetes." *Diabetes Care*, 1999, 22 (12), 2004-2010.

File

QOLM Diab Dutch 1999.pdf

Measures

The short-form 12-Item Well-Being Questionnaire (W-BQ12))

Abstract

The objective of this study was to investigate the validity and reliability of the short-form 12-Item Well-Being Questionnaire (W-BQ12). The 12 items were used to construct the three 4-item subscales Negative Well-Being (NWB), Energy (ENE), and Positive Well-Being (PWB), and the 12-item overall scale General Well-Being (GWB).

A total of 1,472 patients with diabetes completed the W-BQ12, the Hospital Anxiety and Depression scale, and the State Trait Anxiety Inventory. Statistics covered Cronbach's alpha, Pearson's correlation, t tests, and logistic regression. Test-retest reliability was studied in a sample of 202 patients who twice completed the W-BQ12, which was supplemented with the Center for Epidemiological Studies Depression scale and the Short Form (SF)-36 Health Survey.

Of the tested subjects, 739 were defined as having type 1 diabetes and 701 as having type 2 diabetes. Cronbach's alpha proved to be high and stable across sex and type of diabetes for all W-BQ12 scales. Test-retest reliability ranged from 0.66 (PWB) to 0.83 (GWB), with a mean interval of 66 +/- 14 days. Convergent validity of the W-BQ12 scales was supported by high correlations with other measures of affect. Of all scales of the first measurement, ENE proved to have the strongest association with self-reported chronic fatigue. NWB and trait anxiety both had the strongest associations with self-reported depression and current treatment by a psychologist/psychiatrist.

The W-BQ12 appeared to be a reliable and valid measure of psychological well-being. This short instrument is easy to administer and

may be considered a useful tool for both clinicians and researchers to assess the psychological well-being of patients with diabetes.

[9] Jacobson, A.M., et al. "Reliability and validity of a diabetes quality-of-life measure for the diabetes Control and Complications Trial (DCCT)." *Diabetes Care*, 1988, 11 (9), 725-732.

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Not available

Measures

Diabetes quality-of-life (DQOL) measure oriented toward the patient with insulin-dependent diabetes mellitus (IDDM)

Abstract

The author developed a diabetes quality-of-life (DQOL) measure oriented toward the patient with insulin-dependent diabetes mellitus (IDDM). The DQOL was assessed for its reliability and validity in a group of patients with IDDM (n = 192). The authors found that the DQOL and its four scales had high degrees of internal consistency (Cronbach's $r = .66-.92$) and excellent test-retest reliability ($r = .78-.92$). Using conceptually relevant measures of psychiatric symptoms, perceived well-being and adjustment to illness, the authors also demonstrated convergent validity of the DQOL. This instrument was initially designed for use in the Diabetes Control and Complications Trial, a multicenter controlled clinical trial evaluating the effects of two different diabetes treatment regimens on the appearance and progression of early vascular complications. However, the DQOL may also be useful in evaluating the quality of life in other groups of patients with IDDM.

[10] Jacobson, AM., et al. "The evaluation of two measures of quality of life in patients with type I and type II diabetes." *Diabetes Care*, 1994, Vol 17, Issue 4 267-274.

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Not Available

Measures

Diabetes Quality of Life Measure (DQOL) and the Medical Outcome Study Health Survey 36-Item Short Form (SF-36)

Abstract

The purpose of this study was to examine the effects of type I and type II diabetes on patient perceptions of their quality of life and compare the psychometric properties of a generic versus a diabetes-specific quality of life measure.

Consecutive outpatients (n = 240) from a large multi-specialty diabetes clinic were studied on a single occasion using two measures of quality of life--Diabetes Quality of Life Measure (DQOL) and the Medical Outcome Study Health Survey 36-Item Short Form (SF-36). No interventions were performed. This study examines three issues: 1) the reliability (internal consistency) of the two measures; 2) the relationship between the DQOL and SF-36 scales; and 3) the influence of clinical patient characteristics, such as number and severity of diabetes complications, on quality of life. Examination of this issue provides information about the construct validity of the two quality of life measures.

The estimates of internal consistency (Cronbach's alpha) for the DQOL and SF-36 subscales ranged from 0.47 to 0.97. These values were very similar to the published findings from previous studies. The subscales of the two measures were variably correlated with one another (range of correlations: -0.003 to 0.60), indicating that the areas of functioning addressed by the DQOL and SF-36 overlapped only to a modest degree. Examination of the relationship of demographic factors to the DQOL measures suggests that they are not generally confounded by factors such as education, sex, or duration of diabetes. Health-related quality of life is affected by the marital status of both type I and type II diabetic patients, with separated and divorced individuals generally experiencing lower levels of quality of life.

The quality of life measures were sensitive to clinical characteristics, such as frequency and severity of complications. Even after factors such as marital status and, among type II diabetic patients, type of treatment, patients' severity of diabetes complications was a signifi-

cant predictor of both the diabetes-related and the more broad-based measure of quality of life. For type II diabetic patients, insulin treatment was associated with lower levels of satisfaction with diabetes and greater impact of diabetes on quality of life.

This study provides evidence for the reliability and validity of two measures of quality of life. The two measures examine quality of life from different but complimentary perspectives. The DQOL seems more sensitive to lifestyle issues and contains special questions and worry scales oriented toward younger patients, whereas the SF-36 provides more information about functional health status. Thus, the measures may be used usefully in combination in studies of both type I and type II diabetic patients.

[11] Jacobson, A.M., et al. "The effects of psychiatric disorders and symptoms on quality of life in patients with Type I and Type II diabetes mellitus." *Quality of Life Research*, Jan. 1997, 6 (1), 11-20.

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QOLM Diab 97.pdf

Measures

Diabetes Quality of Life Measure; Medical Outcome Study Health Survey Short Form (SF-36)

Abstract

The purpose of this study was to evaluate the influence of psychiatric symptoms and illness status on the health-related quality of life (HRQOL) of out-patients with Type I and Type II diabetes mellitus. Using a two-stage design, all patients were assessed by two measures of quality of life (Diabetes Quality of Life Measure; Medical Outcome Study Health Survey) and a psychiatric symptoms checklist (SCL-90R). Patients scoring 63 or greater on the global severity index of the SCL-90R and 30 percent below this cutoff were then evaluated using the Structured Clinical Interview for the DSM-III-R (SCID).

Quality of life in both Type I and Type II diabetes was influenced by the level of current psychiatric symptoms and presence of co-

morbid psychiatric disorder, after controlling for number of diabetic complications (e.g. effect of lifetime psychiatric illness on diabetes-related HRQOL; $F = 46.8$; $df = 3, 135$; $p < 0.005$). These effects were found consistently across specific domains. Both recent and past psychiatric disorders influenced HRQOL. Separate analyses comparing patients with and without depression showed similar effects. No interaction effects between diabetes type, number of complications, and psychiatric status were found in analyses.

Finally, increased severity of psychiatric symptoms was correlated with decreased HRQOL in patients without current, recent, or past psychiatric diagnosis. This study shows the consistent, independent contribution of psychiatric symptoms and illness to the HRQOL of patients with a co-existing medical illness. Thus, psychiatric interventions addressing common conditions, such as depression, could improve the HRQOL of patients without changing medical status.

[12] Kohen, D., et al. "The role of anxiety and depression in quality of life and symptom reporting in people with diabetes mellitus." *Quality of Life Research*, 1998, 7 (3), 197-204.

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QOLM Diab Mental 98.pdf

Measures

Quality of life rating

Abstract

Although quality of life evaluations are widely used throughout medicine, relatively little is known about the psychological processes involved in making these judgments. What is known is that quality of life judgments are not straightforwardly associated with objective measures of health status or clinician ratings. In particular, patient affect appears to be associated with quality of life ratings but whether this relationship is secondary to physical health or not is controversial. The aim of this study was to determine the role of anxiety and depression in the reporting of quality of life in a group of patients with diabetes mellitus.

One hundred consecutive patients with diabetes (insulin-dependent diabetes mellitus n = 36 and non-insulin-dependent diabetes n = 64) were assessed using a self-report measure of quality of life, a symptom checklist and a questionnaire measure of anxiety and depression. In addition, they were independently rated for their level of physical impairment. The results showed that depression and, to a lesser extent, anxiety were significantly related to self-reported quality of life even when the differences in physical health and age were controlled for statistically. This study shows that, independent of the level of physical illness, affect, particularly depressive affect, is an important factor in the determination of quality of life.

[13] Larsson, D., Lager and P. Nilsson. "Socio-economic characteristics and quality of life in diabetes mellitus- relation to metabolic control." *Scandinavian Journal of Public Health*, 1999, 27, 101-106.

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QOLM Diab Larsson.pdf

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

Diabetes mellitus is a chronic metabolic disease with wide implications for well-being and social life. The aim of this cross-sectional, observational study was to describe possible differences in clinical characteristics, socio-economic factors and quality of life between diabetes patients in poor and good/acceptable metabolic control, as defined by levels of glycated haemoglobin A1c.

From a population-based register of diabetes patients at a clinical chemistry department, the authors selected 96 subjects in poor metabolic control (HbA1c > 10 percent), and 96 subjects in good/acceptable (HbA1c 6.5-7.5 percent) metabolic control, matched for sex, age and duration of diabetes. Each participant was sent a self-administered questionnaire regarding medical history,

family situation and socio-economic background, as well as self-rated health based on a validated instrument (SF-36).

The diabetes patients in poor metabolic control reported more retinopathy, vascular complications and nervous problems than did the patients in acceptable metabolic control. Furthermore, the group in poor metabolic control was also characterized by a lower educational level, a higher number of sick leave days or disability pension and a lower degree of physical activity. Both of the diabetic groups reported lower scorings for physical functioning, general health, vitality and mental health, than did a comparable non-diabetic group from another study.

In summary, diabetic patients in poor metabolic control have a lower educational level and report more complications, nervous problems, sick leave days and disability pensions than patients in good/acceptable metabolic control. The lower degree of physical activity adds to the problems of the first group and should be the target for intervention to achieve better metabolic control.

[14] Bech, P., et al. "The WHO (Ten) well-being index: validation in diabetes." *Psychotherapy and Psychosomatics*, 1996, 65, 183-190.

File

Not Available

Measures

28-item WHO Well-Being Questionnaire, covering four dimensions of depression, anxiety, energy and positive well-being

Abstract

In a European trial in 8 countries, the subjective well-being of patients on alternative forms of treatment for insulin-dependent diabetes was compared using the 28-item WHO Well-Being Questionnaire, covering four dimensions of depression, anxiety, energy and positive well-being. The objective of the analysis reported here has been to identify the items of the WHO questionnaire which belong to an overall index of negative and positive well-being.

Adult patients at 10 study centers in 8 countries who had been on insulin for at least 2 years were invited to participate in a randomized, cross-over trial to compare insulin pump treatment with injection therapy. At each phase, patients completed questions on well-being and general health. Internal validity of the well-being index was evaluated by Cronbach's alpha and Loevinger's and Mokken's homogeneity coefficients, as well as factor analysis. External validity was evaluated by comparisons with results of the general assessment questions and by the ability to discriminate between the alternative forms of treatment.

358 patients had sufficient data for analysis. Ten items were found to constitute a valid index of well-being with respect to internal and external validity. Coefficients of homogeneity were acceptable and there was evidence for both concurrent and discriminant validity.

The WHO (Ten) well-being index includes negative and positive aspects of well-being in a single uni-dimensional scale. Its advantage lies in its ability to show overall change along the continuum of well-being, thus facilitating comparisons between patient groups and treatments. It is not specific to diabetes, and therefore may be useful as a disease-independent index of well-being in a broad range of health care studies.

[15] Smith, D.W. "The population perspective on quality of life among Americans with diabetes." *Quality of Life Research*, 2004, 13, 1391-1400.

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QOLM Diab Smith 2004.pdf

Measures

Days in the last month of limited activity, poor physical health, poor mental health, pain, depression, stress, poor sleep, and high energy and perceived general health)

Abstract

Quality of life (QOL) among Americans with diabetes was compared to Americans without diabetes using the Behavioral Risk Fac-

tor Surveillance System for 1996 through 2000. QOL was measured in terms of days in the last month of limited activity, poor physical health, poor mental health, pain, depression, stress, poor sleep, and high energy and perceived general health. Each of 42,154 diabetics was matched with one non-diabetic (control) respondent on age, sex, race, and ethnicity. Additional statistical adjustments were made for socio-economic status, marital status, and access to health care.

Respondents with diabetes averaged more statistically adjusted impaired days than controls: 3.11 days (SE = 0.07) for physical health, 0.92 (SE = 0.06) for mental health, 1.69 (SE = 0.06) for limited activity, 1.86 (SE = 0.16) for pain, 1.14 (SE = 0.14) for depression, 1.11 (SE = 0.16) for stress, 1.47 (SE = 0.18) for inadequate rest or sleep, and 3.54 (SE = 0.21) fewer for high energy. General health was also lower. Diabetes compromised QOL a substantial proportion of time on every dimension tested. Across the board, lower education, being unable to work, unemployed, or retired and lacking funds to pay for needed medical care were associated with greater impairments among persons with diabetes.

[16] Paschalides, C., et al. "The associations of anxiety, depression and personal illness representations with glycaemic control and health-related quality of life in patients with type 2 diabetes mellitus." *Journal of Psychosomatic Research*, 2004, 57(6), 557-564.

File

QOLM Diab Paschalides 2004.pdf

Measures

Illness Perception Questionnaire (IPQ), the Well-Being Scale (WBQ) and the Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

This study examined the interrelationships of anxiety, depression and personal illness representations with glycaemic control and health-related quality of life in adults with Type 2 diabetes.

One hundred eighty-four consecutive patients with Type 2 diabetes mellitus completed the Illness Perception Questionnaire (IPQ), the Well-Being Scale (WBQ) and the Short Form 36 Health Survey Questionnaire (SF-36). Demographic characteristics, details of diabetes status (duration of diabetes, treatments and complications) and glycosylated haemoglobin (HbA1c) were recorded.

Depression was correlated with greater perceived symptom load ($r = .48, P < .01$), worse anticipated consequences ($r = -.41, P < .01$) and perceived lack of control of diabetes ($r = .28, P < .01$). After controlling for demographic and illness characteristics, personal illness representations relating to symptom load and anticipated consequences were independently associated with the SF-36 physical functioning score, contributing an additional 15 percent to the variance. WBQ depression and anxiety scores, along with IPQ control and consequences, were independently associated with SF-36 mental function score, contributing a further 51 percent to the variance after controlling for demographic and illness details. Neither IPQ nor WBQ scales were associated with HbA1c after controlling for demographic and medical illness details.

Anxiety, depression and negative beliefs about illness influence physical and mental functioning, but not metabolic control in patients with diabetes.

[17] Lange, L.J., and J.D. Piette, J.D. "Perceived health status and perceived diabetes control: psychological indicators and accuracy." *Journal of Psychosomatic Research*, 2005, 58(2), 129-138.

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QOLM Diab Lange 2005.pdf

Measures

The authors examined three types of determinants of patients' health perceptions: physical health indicators (symptoms, comorbid diagnoses, and glycosylated hemoglobin or HbA1c levels), psychological health indicators (general mental health and diabetes-related worry), and socio-demographic factors (age, race, gender, income, and education)

Abstract

The aim of this study is to assess the association of psychological, as well as physical and socio-demographic, indicators with patients' ratings of personal health status and diabetes control and to investigate the association of mental health and depression with errors in the perception of diabetes control.

A socio-demographically diverse sample of 623 diabetes patients was recruited from the general medicine clinics of a county health care system and a Veterans Affairs health care system. The authors examined three types of determinants of patients' health perceptions: physical health indicators (symptoms, comorbid diagnoses, and glycosylated hemoglobin or HbA1c levels), psychological health indicators (general mental health and diabetes-related worry), and socio-demographic factors (age, race, gender, income, and education).

After controlling for patient' socio-demographic characteristics, perceived general health was associated with patients' symptom burden and emotional distress (but not with patients' HbA1c levels). Perceived diabetes control additionally was associated with HbA1c and diabetes-related worries. Further analyses showed that both mental health and diagnosed depression were associated with errors in personal appraisals of diabetes control, with depressed patients more often inaccurately assessing their glycemic control as poor (false-positive error) and non-depressed patients more often missing poor HbA1c levels (false-negative error).

Findings indicate that patients use a comprehensive model for assessing their general health and that depression may lead to more accurate assessments of poor glucose control.

[18] Gallo, J.J., et al. "Depression, cardiovascular disease, diabetes, and two-year mortality among older, primary-care patients."

American Journal of Geriatric Psychiatry, 2005, 13(9), 748-755.

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QOLM Diab Gallo 2005.pdf

Measures

Mortality

Abstract

Depression is a major contributor to death and disability, but few follow-up studies of depression have been carried out in the primary-care setting. The authors sought to assess whether depression in older patients is associated with increased mortality after a 2-year follow-up interval and to estimate the population-attributable fraction (PAF) of depression on mortality in older primary-care patients.

Longitudinal cohort analysis was carried out in 20 primary-care practices. Participants were identified through a two-stage, age-stratified (60-74 or 75+) depression screening of randomly sampled patients; enrollment included patients who screened positive and a random sample of screened-negative patients. In all, 1,226 persons were assessed at baseline. Vital status at 2 years was the outcome of interest.

Of 1,226 persons in the sample, 598 were classified as depressed. After 2 years, 64 persons had died. Persons with depression at baseline were more likely to die at the end of the 2-year follow-up interval than were persons without depression, even after accounting for potentially influential covariates such as whether the participant reported a history of myocardial infarction (MI) or diabetes.

Among older, primary-care patients over the course of a 2-year follow-up interval, depression contributed as much to mortality as did MI or diabetes.

Heart (13)

[1] Barton, Cole, et al. "Quality of Life Measures and Gender Comparisons in North Carolina Cardiac Rehabilitation Programs." *Journal of Cardiopulmonary Rehabilitation*. Jan/Feb 2001, 21(1): 37-46.

File

QOL Diab Burton 2001.html

Measures

QOL index domains measured were health/function, psychological/spiritual status, socioeconomic status, and family interaction

Abstract

Quality of life (QOL) is an important health-related outcome measure in patients with cardiovascular disease. The North Carolina Cardiopulmonary Rehabilitation Association (NCCRA) is a coalition of 72 state-certified, multidisciplinary cardiac rehabilitation (CR) programs. In 1997, the NCCRA Executive Board and Research Committee agreed to collect ongoing data to assess QOL changes following CR participation using the Ferrans & Powers QOL Index Cardiac Version III. The purpose of this study was to determine if changes were present in QOL scores after 12 weeks of CR in men and women from multiple outpatient centers.

Data were analyzed from 420 patients from 19 Phase II early outpatient CR programs who completed the QOL index survey within the first week of program entry and upon discharge. The four QOL index domains measured were health/function, psychological/spiritual status, socioeconomic status, and family interaction. Overall QOL was tabulated as the aggregate score from the four domains. Each domain, as well as overall QOL, was compared pre- and post-CR participation with a repeated measures analysis of variance.

Across programs, statistically significant improvements in QOL indices were observed following 12 weeks of CR in each of the four domains and on the overall score in all patients. Men reported greater CR entry and discharge scores than women on the health/function, family interaction, and overall scores. Women showed a greater positive change in scores than men on the socioeconomic, family interaction, and overall scores.

Patients who participated in Phase II multidisciplinary North Carolina CR programs and completed the protocol improved QOL parameters. While men had higher physical function and overall QOL scores both pre- and post-CR, women showed greater improvements in overall scores, as well as in family and socioeconomic parameters. These findings suggest that North Carolina CR patients experience

a positive change in QOL following short-term participation in CR. Further study with a larger number of patients benchmarked with programs from other regions with comparisons to patients who do not participate in formalized CR programs is indicated from this investigation.

[2] Masoudi, FA., et al. “Cardiovascular Outcomes Research Consortium. Age, functional capacity, and health-related quality of life in patients with heart failure.” *J Card Fail*, 2004, 10(5):368-373.

File

QOLM Heart Masoudi 2004.pdf

Measures

The Kansas City Cardiomyopathy Questionnaire (KCCQ)

Abstract

Although heart failure disproportionately affects older persons and is associated with significant physical disability, existing data on physical limitations and health-related quality of life (HRQL) derive largely from studies of younger subjects. The authors compared the relationship between functional limitation and HRQL between older and younger patients with heart failure.

The authors evaluated 546 outpatients with heart failure enrolled in a multicenter prospective cohort study. At baseline and 6 +/- 2 weeks later, functional status was assessed by New York Heart Association (NYHA) classification and 6-minute walk testing. HRQL was measured with the Kansas City Cardiomyopathy Questionnaire (KCCQ). Comparing older (age >65 years, n = 218) and younger patients (n = 328), the authors assessed baseline HRQL across strata of functional status. In the 484 patients who completed follow-up (194 older and 290 younger patients), the authors also assessed the changes in HRQL associated with changes in functional status over time. At baseline, older patients had better HRQL than younger patients (mean KCCQ score 60 +/- 25 versus 54 +/- 28, P = .005) in spite of worse NYHA class (mean 2.54 versus 2.35, P < .001) and lower 6-minute walk distances (824 +/- 378 versus 1064 +/- 371 feet, P < .001).

After multivariable adjustment including baseline NYHA class, older age was independently correlated with better HRQL (beta = +7.9 points, $P < .001$). At follow-up, older patients with a deterioration in NYHA class experienced marked declines in HRQL compared with younger patients (mean HRQL change of -14.4 points versus +0.3 points, respectively, $P < .001$). Analyses using 6-minute walk distance as the functional measure yielded similar results.

Although older patients with heart failure have relatively good HRQL in spite of significant functional limitations, they are at risk for worsening HRQL with further decline in functional status. These results underscore the importance of treatments aimed at maintaining functional status in older persons with heart failure, including those with significant baseline functional limitations.

[3] Oliver, J. P., et al. "Measuring the quality of life of severely mentally ill people using the Lancashire Quality of Life Profile." *Social Psychiatry and Psychiatric Epidemiology*, 1997, 32(2), 76-83.

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Not Available

Measures

Lancashire Quality of Life Profile (LQOLP)

Abstract

Quality of life (QOL) has become an important outcome measure for many disorders, including mental illness. The Lancashire Quality of Life Profile (LQOLP) was developed for use in operational contexts, and has been translated into several languages. It is in use in several European and North American community psychiatric services. The present paper addresses the questions: how easy is it to use?; how reliable is it?; do the results of the LQOLP vary by setting in a meaningful way?; how do the results co-vary with measures of clinical symptoms and social functioning?; how well does it measure change?; is it clinically useful? While most of the answers to these questions are favorable, there is a need for further research and development of the profile, in particular with reference to the consequences of the use of the profile as a routine monitoring

instrument and the most appropriate form of statistical analysis in longitudinal data-sets.

[4] Rumsfeld JS., et al. "History of depression, angina, and quality of life after acute coronary syndromes." *Am Heart J*, 2003, 145(3):493-499.

[Cardiology, Denver VA Medical Center, Denver]

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QOLM Heart Rumsfeld 2003.pdf

Measures

Seattle Angina Questionnaire)

Abstract

Depression has been associated with higher mortality and morbidity rates after acute coronary syndromes (ACS), but little is known about the association between depression, angina burden, and quality of life. The authors evaluated the association between a history of depression and patient-reported angina frequency, physical limitation, and quality of life 7 months after discharge from the hospital for ACS.

Patients were enrolled in the Department of Veterans Affairs Access to Cardiology Study, a cohort study of all patients with acute myocardial infarction or unstable angina who were discharged from 24 Veterans Affairs medical centers between March 1998 and February 1999. Data from 1957 patients who completed a 7-month post discharge Seattle Angina Questionnaire were analyzed. Multivariate logistic regression was used to evaluate a history of depression as an independent predictor of angina frequency, physical limitation, and quality of life 7 months after ACS, as measured with the Seattle Angina Questionnaire.

A total of 526 patients (26.7 percent) had a history of depression. After adjustment for a wide array of demographic, cardiac, and comorbid factors, a history of depression was significantly associated with more frequent angina (odds ratio [OR] 2.40, 95 percent CI

1.86-3.10, $P < .001$), greater physical limitation (OR 2.89, 95 percent CI 2.17-3.86, $P < .001$), and worse quality of life (OR 2.84, 95 percent CI 2.16-3.72, $P < .001$) after ACS.

The authors found a strong association between a history of depression and both heavier angina burden and worse health status after ACS. These findings further support the importance of depression as a risk marker for adverse outcomes after ACS.

[5] Ruo, Bernice, et al. 2003. "Depressive Symptoms and Health Related Quality of Life: The Heart and Soul Study." *JAMA*, 2003, 290: 215-221.

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QOLM Heart Jama 2003.pdf

Measures

Patient Health Questionnaire (PHQ)

Abstract

Little is known regarding the extent to which patient-reported health status, including symptom burden, physical limitation, and quality of life, is determined by psychosocial versus physiological factors among patients with chronic disease. This study compared the contributions of depressive symptoms and measures of cardiac function to the health status of patients with coronary artery disease.

A cross-sectional study of 1024 adults with stable coronary artery disease recruited from outpatient clinics in the San Francisco Bay Area between September 2000 and December 2002. Measurement of depressive symptoms using the Patient Health Questionnaire (PHQ); assessment of cardiac function by measuring left ventricular ejection fraction on echocardiography, exercise capacity on treadmill testing, and ischemia on stress echocardiography; and measurement of a range of health status outcomes, including symptom burden, physical limitation, and quality of life, using the Seattle Angina Questionnaire. Participants were also asked to rate their overall health as excellent, very good, good, fair, or poor.

Of the 1024 participants, 201 (20 percent) had depressive symptoms (PHQ score 10). Participants with depressive symptoms were more likely than those without depressive symptoms to report at least mild symptom burden (60 percent versus 33 percent; $P < .001$), mild physical limitation (73 percent versus 40 percent; $P < .001$), mildly diminished quality of life (67 percent versus 31 percent; $P < .001$), and fair or poor overall health (66 percent versus 30 percent; $P < .001$). In multivariate analyses adjusting for measures of cardiac function and other patient characteristics, depressive symptoms were strongly associated with greater symptom burden (odds ratio [OR], 1.8; 95 percent confidence interval [CI], 1.3-2.7; $P = .002$), greater physical limitation (OR, 3.1; 95 percent CI, 2.1-4.6; $P < .001$), worse quality of life (OR, 3.1; 95 percent CI, 2.2-4.6; $P < .001$), and worse overall health (OR, 2.0; 95 percent CI, 1.3-2.9; $P < .001$). Although decreased exercise capacity was associated with worse health status, left ventricular ejection fraction and ischemia were not.

Among patients with coronary disease, depressive symptoms are strongly associated with patient-reported health status, including symptom burden, physical limitation, quality of life, and overall health. Conversely, 2 traditional measures of cardiac function—ejection fraction and ischemia—are not. Efforts to improve health status should include assessment and treatment of depressive symptoms.

[6] Spertus JA., et al. “Predictors of quality-of-life benefit after percutaneous coronary intervention.” *Circulation*, 2004, 110(25): 3789-94.

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QOLM Heart Spertus 2004.pdf

Measures

Seattle Angina Questionnaire (SAQ)

Abstract

Improving patients' quality of life is a primary indication for percutaneous coronary intervention (PCI), yet little is known about patient characteristics associated with greater quality-of-life improvement from the procedure. This study was conducted to identify patient characteristics associated with quality-of-life benefit after PCI.

A consecutive series of 1518 patients undergoing PCI in nonacute myocardial infarction settings were prospectively enrolled into an observational study documenting their post-procedural health status. The authors examined univariate and multivariable associations between baseline patient characteristics and quality of life 1 year after the procedure using the disease-specific Seattle Angina Questionnaire (SAQ) to quantify the impact of patients' coronary disease on their quality of life. Baseline angina frequency and physical function were the strongest predictors of quality-of-life improvement 1 year after PCI. In comparing patients without angina to those experiencing monthly, weekly, and daily angina, the quality-of-life improvements (mean \pm SEM) were 21.4 \pm 2.1, 30.7 \pm 2.2, and 34.6 \pm 2.6 points greater ($P<0.001$). Patients with mild, moderate, and severe physical limitation improved 13.8 \pm 1.9, 20.0 \pm 2.1, and 13.5 \pm 3.5 points more than those with minimal baseline physical limitation ($P<0.001$). These findings were maintained in multivariable models correcting for baseline differences in demographic, clinical, disease-severity, and health-status variables.

Pre-procedural angina frequency is the most important prognostic indicator of quality-of-life improvement after PCI. Although substantial quality-of-life benefits are attained in most patients with pre-procedural angina, more careful consideration of the potential benefits and risks of the procedure are needed in asymptomatic patients.

[7] Spertus JA., et al. "Development and evaluation of the Seattle Angina Questionnaire: a new functional status measure for coronary artery disease." *J Am Coll Cardiol*, 1995, 25(2):333-341.

[Health Services Research and Development Program, Seattle Veterans Affairs Medical Center]

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QOLM Heart Spertus 95.pdf

Measures

The Seattle Angina Questionnaire

Abstract

This study sought to establish the validity, reproducibility and responsiveness of the Seattle Angina Questionnaire, a 19-item self-administered questionnaire measuring five dimensions of coronary artery disease: physical limitation, anginal stability, anginal frequency, treatment satisfaction and disease perception. Assessing the functional status of patients is becoming increasingly important in both clinical research and quality assurance programs. No current functional status measure quantifies all of the important domains affected by coronary artery disease.

A cross-sectional or serial administration of the Seattle Angina Questionnaire was carried out in four groups of patients: 70 undergoing exercise treadmill testing, 58 undergoing coronary angioplasty, 160 with initially stable coronary artery disease and an additional 84 with coronary artery disease. Evidence of validity was sought by comparing the questionnaire's five scales with the duration of exercise treadmill tests, physician diagnoses, nitroglycerin refills and other validated instruments. Reproducibility and responsiveness were assessed by comparing serial responses over a 3-month interval.

All five scales correlated significantly with other measures of diagnosis and patient function ($r = 0.31$ to 0.70 , $p < \text{or} = 0.001$). Questionnaire responses of patients with stable coronary artery disease did not change over 3 months. The questionnaire was sensitive to both dramatic clinical change, as seen after successful coronary angioplasty, and to more subtle clinical change, as seen among outpatients with initially stable coronary artery disease.

The Seattle Angina Questionnaire is a valid and reliable instrument that measures five clinically important dimensions of health in patients with coronary artery disease. It is sensitive to clinical change and should be a valuable measure of outcome in cardiovascular research.

[8] Spertus JA., et al. "Monitoring the quality of life in patients with coronary artery disease." *Am J Cardiol*, 1994, 74(12):1240-1244.

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Measures

The Short Form-36

Abstract

Monitoring the outcomes of treatment and quantifying patients' functional status have assumed a prominent role in both clinical trials and quality assurance programs. Because patients with coronary artery disease (CAD) may have comorbid illnesses, and because generic health status questionnaires may not focus on symptoms and impairments unique to coronary disease, a generic measure of health status may not be sufficient to detect important changes in patients' CAD. The responsiveness to clinical change of the Seattle Angina Questionnaire (SAQ), a disease-specific measure for CAD, was compared with that of the Short Form-36, a generic measure of health status.

Both questionnaires were serially administered, 3 months apart, to 45 patients undergoing coronary angioplasty and to 130 patients with stable CAD. Most scales of both questionnaires improved significantly after coronary angioplasty. The responsiveness statistics of the SAQ exceeded those of the Short Form-36. Among 130 patients with initially stable angina, 33 deteriorated, 79 remained stable, and 18 improved over 3 months of observation. Mean SAQ scores changed significantly and appropriately in each of these groups. In contrast, none of the Short Form-36 scales detected these more subtle changes.

Although useful in assessing overall function, a generic health status measure, such as the Short Form-36, may not be responsive enough to detect important clinical changes in patients' CAD. A disease-specific instrument, such as the SAQ, can be an important and relevant outcome measure in clinical trials or quality assurance programs.

[9] Spitzer RL, et al. "Health-Related Quality Of Life In Primary Care Patients With Mental Disorders: Results of the PRIME-MD 1000 study." *JAMA*, 1995 274:1511-1517.

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Measures

The six scales of the Short-Form General Health Survey and self-reported disability day

Abstract

To determine if different mental disorders commonly seen in primary care are uniquely associated with distinctive patterns of impairment in the components of health-related quality of life (HRQL) and how this compares with the impairment seen in common medical disorders. Four primary care clinics. A total of 1000 adult patients (369 selected by convenience and 631 selected by site-specific methods to avoid sampling bias) assessed by 31 primary care physicians using PRIME-MD (Primary Care Evaluation of Mental Disorders) to make diagnoses of mood, anxiety, alcohol, somatoform, and eating disorders

The study uses the six scales of the Short-Form General Health Survey and self-reported disability days, adjusting for demographic variables as well as psychiatric and medical comorbidity. Mood, anxiety, somatoform, and eating disorders were associated with substantial impairment in HRQL. Impairment was also present in patients who only had sub-threshold mental disorder diagnoses, such as minor depression and anxiety disorder not otherwise specified. The study found that mental disorders, particularly mood disorders, accounted for considerably more of the impairment on all domains of HRQL than did common medical disorders.

Finally, the study found marked differences in the pattern of impairment among different groups of mental disorders just as others have reported unique patterns associated with different medical disorders. Whereas mood disorders had a pervasive effect on all domains of HRQL, anxiety, somatoform, and eating disorders affected only selected domains.

Mental disorders commonly seen in primary care are not only associated with more impairment in HRQL than common medical disorders, but also have distinct patterns of impairment. Primary care directed at improving HRQL needs to focus on the recognition and treatment of common mental disorders. Outcomes studies of mental disorders in both primary care and psychiatric settings should include multidimensional measures of HRQL.

[10] Harrison, M.B., et al. "Quality of life of individuals with heart failure- A randomized trial of the effectiveness of two models of hospital-to-home transition." *Medical Care*, 2002, 40 (4), 271-282.

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QOLM Heart Harrison 2002.pdf

Measures

Minnesota Living with Heart Failure Questionnaire (MLHFQ), Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The growing number of patients with congestive heart failure has increased both the pressure on hospital resources and the need for community management of the condition. Improving hospital-to-home transition for this population is a logical step in responding to current practice guidelines' recommendations for coordination and education. Positive outcomes have been reported from trials evaluating multiple interventions, enhanced hospital discharge, and follow-up through the addition of a case management role. The question remains if similar gains could be achieved working with usual hospital and community nurses.

A 12-week, prospective, randomized controlled trial was conducted of the effect of transitional care on health-related quality of life (disease-specific and generic measures), rates of readmission, and emergency room use. The nurse-led intervention focused on the transition from hospital-to-home and supportive care for self-management 2 weeks after hospital discharge

At 6 weeks after hospital discharge, the overall Minnesota Living with Heart Failure Questionnaire (MLHFQ) score was better among the Transitional Care patients (27.2 +/- 19.1 SD) than among the Usual Care patients (37.5 +/- 20.3 SD; P = 0.002). Similar results were found at 12 weeks post discharge for the overall MLHFQ and at 6- and 12-weeks post discharge for the MLHFQ's Physical Dimension and Emotional Dimension subscales. Differences in generic quality life, as assessed by the SF-36 Physical component, Mental Component, and General Health subscales, were not significantly different between the Transition and Usual Care groups. At 12 weeks post discharge, 31 percent of the Usual Care patients had been readmitted compared with 23 percent of the Transitional Care patients (P = 0.26), and 46 percent of the Usual Care group visited the emergency department compared with 29 percent in the Transitional Care group ($\chi^2 = 4.86$, df 1, P = 0.03).

There were significant improvements in health-related quality of life (HRQL) associated with Transitional Care and less use of emergency rooms.

[11] Lukkarinen, H., and M. Hentinen. "Assessment of quality of life with the Nottingham Health Profile among patients with coronary heart disease." *Journal of Advanced Nursing* 1997, 26, 73-84.

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QOLM Heart Lukkarinen 1997.pdf

Measures

The modified Patient Generated Index (PGI), a generic instrument (the Short Form 36) and a disease-specific instrument (the Quality of Life after Myocardial Infarction questionnaire)

Abstract

Increasing emphasis is being placed on the evaluation of health-related quality of life. However, there is no consensus on the definition of this concept and as a result there are a plethora of existing measurement instruments. Head-to-head comparisons of the psychometric properties of existing instruments are necessary to facili-

tate evidence-based decisions about which instrument should be chosen for routine use. Therefore, an individualized instrument (the modified Patient Generated Index (PGI)), a generic instrument (the Short Form 36) and a disease-specific instrument (the Quality of Life after Myocardial Infarction questionnaire) were administered to patients with ischaemic heart disease (n = 117) and the evidence for the validity, reliability and sensitivity of each instrument was examined and compared.

The modified PGI compared favorably with the other instruments but none of the instruments examined provided sound evidence for sensitivity to change. Therefore, any recommendation for the use of the individualized approach in the routine collection of health-related quality of life data in clinical practice must be conditional upon the submission of further evidence to support the sensitivity of such instruments.

[12] Bennett, S.J., Oldridge, et al. "Comparison of quality of life measures in heart failure." *Nursing Research*, 2003, 52 (4), 207-216.

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QOLM Heart 2003.pdf

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

Thyroid carcinoma requires lifelong monitoring with serum thyroglobulin (Tg), radioactive iodine whole body scanning (WBS) and other imaging modalities. Levothyroxine (L-T4) withdrawal for Tg measurement and WBS increases these tests' sensitivities but causes hypothyroidism. Recombinant TSH (rhTSH) enables testing without L-T4 withdrawal. The purpose of the study was to examine the impact of short-term hypothyroidism on the health-related quality of life (HRQOL) of patients after rhTSH versus L-T4 withdrawal. The SF-36 Health Survey was administered to 228 patients at three time points: on L-T4, after rhTSH, and after L-T4 withdrawal. The

study team conducted intervention of the administration of rhTSH on L-T4, and withdrawal from thyroid hormone.

Mean SF-36 scores were compared during the two interventions, and to the U.S. general population and patients with heart failure, depression and migraine headache. Patients had SF-36 scores at or above the norm for the general U.S. population in 6 of 8 domains at baseline on L-T4 and in 7 of 8 domains after rhTSH. Patients' scores declined significantly in all 8 domains after L-T4 withdrawal when compared with the other two periods ($P < 0.0001$). Patients' HRQOL scores while on L-T4 and after rhTSH, were at or above those for patients with heart failure, depression, and migraine in all 8 domains. After L-T4 withdrawal, patients' HRQOL scores were significantly below CHF, depression, and migraine norms in 6, 3, and 6 of the 8 domains, respectively.

The study found that short-term hypothyroidism after L-T4 withdrawal is associated with a significant decline in quality of life that is abrogated by rhTSH use.

[13] Valkamo, M., et al. "Life satisfaction in patients with chest pain subsequently diagnosed as coronary heart disease- connection through depressive symptoms." *Quality of Life Research*, 2003, 12, 1099-1105.

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QOLM Heart Valkamo 2003.pdf

Measures

Four-item life satisfaction scale (LS), depression with the 21-item Beck Depression Inventory (BDI) and other psychiatric symptoms with the symptom check list (SCL)

Abstract

The aim of this study was to investigate factors associated with life dissatisfaction in symptomatic patients ($n = 144$) with chest pain subsequently diagnosed as coronary heart disease (CHD) by coronary angiography. Life dissatisfaction was assessed with a four-item life satisfaction scale (LS), depression with the 21-item Beck Depres-

sion Inventory (BDI) and other psychiatric symptoms with the symptom check list (SCL). DSM-III-R Axis I and Axis II psychiatric diagnoses were performed by means of the Structured Clinical Interview. All assessments took place one day before angiography. Twenty-four per cent of CHD patients were dissatisfied with their lives.

Life dissatisfaction was associated with being unmarried. Dissatisfied patients had Axis I mental disorders and Axis II personality disorders more frequently than others. Psychiatric and depressive symptoms according to the SCL and BDI, respectively, were also higher among dissatisfied patients. In multiple logistic regression analyses, mental disorders were related to life dissatisfaction when age, sex, employment status, New York Heart Association class, duration of chest pain symptoms and workload were controlled in the model. Married subjects had a lower probability of being dissatisfied with their lives than other subjects (Odds Ratio, OR: 0.23). When BDI scores were included in the model, the only factor independently associated with life dissatisfaction was the severity of depressive symptoms (OR: 1.81). To conclude, life dissatisfaction is not primarily determined by the severity of CHD but by the existence of depressive symptoms.

Breathing (13)

[1] Linder JA., et al. "Measures of Health-Related Quality of Life for Adults with Sinusitis: A Systematic Review." *J Gen Intern Med*, 2003, 18:390-401.

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Measures

Chronic Sinusitis Survey, the Rhinosinusitis Outcome Measure-31, and the Sinonasal Outcome Test-16

Abstract

Symptoms suggestive of acute sinusitis are a common reason for patients to visit primary care providers. Since objective measures of outcome have not been shown to be related to patient reported outcomes, measures of treatment success have focused on symptom relief and improved health-related quality of life (HRQL). Assessing the appropriate role of treatment - for example, antibiotics for patients with acute sinusitis - requires valid, reliable, and responsive measures of outcome. The authors identified symptom scores and HRQL instruments for adults with sinusitis and assessed their performance characteristics.

Articles were identified through computer searches of the medline, premedline, and embase databases, the Cochrane Library, and internet documents; inquiries to experts in sinusitis and outcomes assessment; and review of reference lists. Studies that used HRQL instruments or evaluated the performance characteristics of symptom scores in adults with sinusitis, published in English after 1966, were identified. Two reviewers independently extracted data on study design, setting, and patient characteristics; instrument length and format; and instrument validity, reliability, responsiveness to change, and interpretability. Study quality was assessed using a 10-point score.

Of 1,340 articles in the original search, 29 articles using 16 HRQL instruments and 5 symptoms scores met inclusion and exclusion criteria. The overall quality of these studies was low; only 4 studies scored higher than 4 of 10 points. Four studies included patients with acute sinusitis, but only 2 included exclusively acute sinusitis patients. Three instruments have been shown to meet basic requirements for validity, reliability, and responsiveness: the Chronic Sinusitis Survey, the Rhinosinusitis Outcome Measure-31, and the Sinonasal Outcome Test-16. No instrument has been validated in a primary care setting or for patients with acute sinusitis.

Few validated measures of sinusitis-specific HRQL are available. The 3 instruments shown to be valid, reliable, and responsive have been assessed in patients with chronic sinusitis. No measure has been validated in primary care settings or for patients with acute sinusitis. A lack of valid, responsive outcome measures may limit current treatment recommendations for patients with acute sinusitis.

[2] Myint PK, et al. “Respiratory Function and Self-Reported Functional Health: EPIC-Norfolk Population Study.” *European Respiratory Journal*, 2005, 26(3):494-502.

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Measures

Self-Reported Functional Health: EPIC-Norfolk Population Study

[3] Sprenkle MD, et al. “The Veterans Short Form 36 Questionnaire Is Predictive Of Mortality And Health Care Utilization in a Population Of Veterans with a Self-Reported Diagnosis Of Asthma or COPD.” *Chest*, 2004, 126(1):81-89.

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QOLM Breathing Sprenkle 2004.pdf

Measures

Veterans Short Form 36 (SF-36V)

Abstract

Measures of health-related quality of life (HRQL) correlate with disease stage in persons with COPD. However, as their predictive capacity for mortality or medical utilization is less well defined, the study sought to examine the relationship of a general measure of HRQL and outcomes in persons with obstructive lung disease. All veterans in Upper Midwest Veterans Integrated Service Network (VISN)-13 (n = 70,017) were surveyed with the Veterans Short Form 36 (SF-36V). Persons with reported asthma or COPD who completed the SF-36V formed the study cohort (n = 8,354).

For purposes of analysis, individuals were divided into quartiles of HRQL according to their physical component summary (PCS) and mental component summary (MCS), values derived from the SF-36V. Outcomes of mortality, hospitalization, and outpatient visits were recorded for 12 months after the survey. Outpatient utilization was dichotomized into high versus low use, with high use being de-

defined as the upper quartile of visits in the 12 months prior to survey mailing. The study cohort had a mean age of 65 years and was largely male (95 percent), both consistent with a veteran population. After correcting for potential confounding factors through multivariable regression, the PCS was independently predictive of death, hospitalization, and high outpatient utilization. When using the first quartile of PCS as the reference population, those in the fourth quartile of PCS had a hazard ratio for death of 5.47 (95 percent confidence interval [CI], 3.63 to 8.26). Similarly, the odds ratios for hospitalization, high primary care visits, and high specialty medicine visits in the fourth quartile of PCS were 1.82 (95 percent CI, 1.51 to 2.19), 1.54 (95 percent CI, 1.26 to 1.87), and 1.46 (95 percent CI, 1.21 to 1.78), respectively. The MCS, through multivariable regression, was predictive of death but unassociated with subsequent hospitalization or high outpatient utilization.

HRQL, as assessed by the SF-36V, is an independent predictor of mortality, hospitalization, and outpatient utilization in persons with self-reported obstructive lung disease.

[4] Osoba, D., et al. "Psychometric properties and responsiveness of the EORTC Quality of Life Questionnaire (QLQ-C30) in patients with breast, ovarian and lung cancer." *Quality of Life Research*, 1994, 3, 353-364.

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Not available

Measures

QLQ-C30, a health-related quality of life questionnaire developed for use in patients with cancer

Abstract

The QLQ-C30, a health-related quality of life questionnaire developed for use in patients with cancer, has been previously validated in patients with lung cancer and head and neck cancer. In this study, further validation was carried out for 535 patients, including patients with breast cancer (n = 143) and ovarian cancer (n = 111) for whom there is no previously published validation, as well as pa-

tients with lung cancer (n = 160) and a heterogeneous group of other cancers (n = 121). All patients were entered in one of two trials of anti-emetics to prevent chemotherapy-induced emesis. The QLQ-C30 was completed before chemotherapy and on day 8 after chemotherapy.

The factor structure in patients with breast and ovarian cancer was similar to that previously described. Interdomain correlations, in the entire group, were strongest for the physical and role function domains and the fatigue, pain and global quality of life domains before and after chemotherapy. In addition, after chemotherapy, social function was also strongly correlated with fatigue and global quality of life. These correlations were not always of equal strength in the breast, ovarian and lung groups, suggesting that there may be differences between these groups. The responsiveness of the QLQ-C30 in the presence of widely metastatic, as compared with locoregional, disease showed changes in the expected directions (i.e., diminished function in physical and social role functions and in global quality of life, with greater fatigue and pain in patients with metastatic disease).

Eight days after chemotherapy, decreases were seen in physical, role and social functioning and in global quality of life, and there was greater fatigue, nausea and vomiting compared with before chemotherapy. Patients with breast cancer had better physical, role and social functioning and less fatigue and pain than patients with ovarian cancer. This result is expected, since many of the patients with breast cancer had early stage disease, whereas those with ovarian cancer had advanced stage disease.

Mean scores for patients with lung cancer were between the other two groups, in keeping with the mixture of early and advanced stage disease in these patients. There was a strong correlation between ECOG performance status scores and several domains of the QLQ-C30; these were all in the expected directions. The results of this study confirm those in earlier studies on patients with lung cancer, and provide new information on patients with breast and ovarian cancer. In addition, the QLQ-C30 is responsive to the effects of chemotherapy and of metastatic disease.

[5] Kaasa, S., et al. "Validation of a quality of life questionnaire for use in clinical trials for treatment of patients with inoperable lung cancer." *European Journal of Cancer and Clinical Oncology*, 1988, 24, 691-701.

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Not available

Measures

Self-administration with 29 variables was designed including the following subjects: psychosocial well-being, medical side-effects, activities of daily living and physical performance

Abstract

In order to assess the quality of life of patients with inoperable lung cancer, a questionnaire for patient self-administration with 29 variables was designed including the following subjects: psychosocial well-being, medical side-effects, activities of daily living and physical performance. The questionnaire was validated by using a semi-structured interview.

Thirty-one patients treated for inoperable lung cancer with either radiotherapy (42 percent), chemotherapy (42 percent) or a combination of these two treatment modalities (16 percent) were included in the study. The multitrait-multimethod matrix (MTMM) was used in the analysis of the construct validity. The present validation study showed a high degree of validity for the majority of the items studied. Some of the items showed a low degree of validity, and are subject to future analysis in large-scale studies.

[6] Lobo, F.S., et al. "Estimation and comparison of derived preference scores from the SF-36 in lung cancer transplant patients." *Quality of Life Research*, 2004, 13, 377-388.

File

Not available

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

[7] Hyland, M.E., et al. "A scale for assessing quality of life in adult asthma sufferers." *Journal of Psychosomatic Research*, 1991, 35, 99-110.

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Measures

Asthma Questionnaire is a 68-item quality of life scale designed to be sensitive to quality of life changes in clinical trials

Abstract

The Asthma Questionnaire is a 68-item quality of life scale designed to be sensitive to quality of life changes in clinical trials. The questionnaire covers 11 domains of life experience, the initial domain and item sets being derived from six qualitative focus groups of asthma patients. Psychometric analysis of responses of 101 asthma patients to the initial 101-item set showed the scale to be unidimensional despite being multi-domain, and the finding of unidimensionality was replicated during the further three stages of item refinement using 783 patients. The scale compensates for acquiescence bias as well as allowing a 'not applicable' response category. Validity of the scale was demonstrated by confirmation of expected group differences and the retest reliability was 0.948.

[8] Hyland, M.E., et al. "Sensitivity of quality of life domains and constructs to longitudinal change in a clinical trial comparing salmeterol and placebo in asthmatics." *Quality of Life Research*, 1994, 3 (2), 121-126.

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Measures

Asthma Questionnaire (LWAQ)

Abstract

The quality of life (QOL) benefits of salmeterol versus placebo were compared in a double-blind, multicentre study using the Living with Asthma Questionnaire (LWAQ) which was scored in three different ways. First, the overall LWAQ score showed that salmeterol enhanced QOL compared to placebo. Second, when the LWAQ was analysed in terms of its two construct subscales they found, as predicted previously, that the Problem construct was more sensitive to longitudinal change compared with the Evaluation construct. Third, when the LWAQ was analysed in terms of its 11 domain subscales they found a significant improvement for salmeterol compared with placebo on three domains, Sport, Sleep, and Work and other activities. Analysing clinical trial results in terms of construct subscales and domain subscales provides different kinds of information each of which is useful. Analysis in terms of overall QOL scores is less informative.

[9] Juniper, E.F., et al. "Measuring quality of life in asthma." *American Review of Respiratory Disease*, 1993, 147, 832-838.

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Measures

Asthma Questionnaire (LWAQ))

Abstract

The aim of this study was to evaluate the measurement properties of an Asthma Quality of Life Questionnaire. The study design was an 8-week unblinded single cohort with assessments at 0, 4, and 8 week. Thirty-nine adults with symptomatic asthma and a wide range of airway responsiveness and medication requirements were enrolled from previous studies and through notices in the local media. Those with inadequately controlled asthma were offered an inhaled steroid (budesonide).

Asthma Quality of Life Questionnaire, spirometry, a clinical asthma control questionnaire, medication requirements, airway responsiveness to methacholine, the Sickness Impact Profile, and the Rand questionnaire were recorded at each visit. Patients kept daily diaries of peak flow rates and medications. The Asthma Quality of Life Questionnaire was able to detect changes in patients who responded to treatment or who had natural fluctuations in their asthma ($p < 0.001$) and to differentiate these patients from those who remained stable ($p < 0.001$). The Questionnaire was reproducible in patients who were stable (intraclass correlation coefficient = 0.92). There were significant longitudinal and cross-sectional correlations between asthma quality of life and other measures of both clinical asthma and generic quality of life.

The authors conclude that the Asthma Quality of Life Questionnaire has good measurement properties and that it is valid as both an evaluative and a discriminative instrument. It measures the component of asthma most important to patients, and it should be considered for inclusion in all asthma studies.

[10] Gelin, M.N., et al. "The dimensionality and gender item functioning of the mini asthma quality of life questionnaire (MINIAQLQ)." *Social Indicators Research*, 2004, 68 (1), 91-106.

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Not available

Measures

Mini-Asthma Questionnaire (LWAQ)

The present study investigated the factor structure and item analysis of the Mini Asthma Quality of Life Questionnaire (MiniAQLQ) in a sample of 258 community-dwelling asthmatic adults between the ages of 16 and 87 years. The mean age was 56 years for males ($N = 99$) and 50 years for females ($N = 159$). This study compared the fit of three factor solutions using a maximum likelihood confirmatory factor analysis. Based on the fit indices, support was found for a hierarchical factor structure with a second-order factor of quality of life and four first-order factors of symptoms, activity limitation, emotional function and environmental stimuli.

Given that the data fit an essentially uni-dimensional model, gender differential item functioning (DIF) was explored using Zumbo's (1999) ordinal logistic regression method with corresponding logistic regression effect size estimators. After matching males and females on the underlying variable of quality of life, gender DIF was found on the cigarette smoke and weather or air pollution items. These findings indicate that gender influences how an individual endorses these particular items on the MiniAQLQ.

[11] Oga, T., et al. "A comparison of the responsiveness of different generic health status measures in patients with asthma." *Quality of Life Research*, 2003, 12, 555-563.

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Not available

Measures

The Medical Outcomes Study Short Form 36-items Health Survey (SF-36), the Nottingham Health Profile (NHP) and the EQ5D (EuroQoL), as well as one disease-specific instrument, the Asthma Quality of Life Questionnaire (AQLQ)

Abstract

Generic health status has been recommended to be measured separately from disease-specific health status, because they can yield complementary information. In particular, generic health status can provide comprehensive health ratings across various disorders. However, the weakness with generic measures is that they may be less responsive to clinical changes than disease-specific ones. Therefore, when using generic health status as an endpoint in clinical trials, the instrument to be used is a problem with respect to responsiveness. In the present study, the authors investigated and compared the responsiveness of health status measures during asthma treatment using three different generic instruments: the Medical Outcomes Study Short Form 36-items Health Survey (SF-36), the Nottingham Health Profile (NHP) and the EQ5D (EuroQoL), as well as one disease-specific instrument, the Asthma Quality of Life Questionnaire (AQLQ).

Fifty-four new patients with asthma who consulted our clinic were recruited. The health status measurements were performed on the initial visit, and at 3 and 6 months. All subscales of the SF-36 showed a significant improvement during the first 6 months. Each dimension of the EQ5D showed stronger ceiling effects than the SF-36. With respect to the responsiveness indices, the SF-36 was regarded as more responsive than the NHP or EQ5D utility. The changes in the SF-36 had a weak to moderate correlation with the changes in the AQLQ. In conclusion, the SF-36 had a higher responsiveness for asthma as a generic measure than the NHP or EQ5D, and evaluated different aspects from the AQLQ. The SF-36 can be used effectively in asthma clinical trials

[12] Hyland, M.E. "Quality of life assessment in Respiratory disease: An examination of the content and validity of four questionnaires." *Pharmaco Economics*, 1992, 2, 43-53.

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Measures

Chronic Respiratory Disease Questionnaire, St George's Respiratory Questionnaire, Living with Asthma Questionnaire, and Asthma Quality of Life Questionnaire

Abstract

Four recent questionnaires for measuring the quality of life of patients with respiratory disease (Chronic Respiratory Disease Questionnaire, St George's Respiratory Questionnaire, Living with Asthma Questionnaire, and Asthma Quality of Life Questionnaire) differ in the content and style of the items used. Differences in content arise over the use or emphasis on symptom items, functional limitation (activity) items, and emotion items. These differences stem in part from the different methods used for item selection and refinement, which include selecting the most 'important' items, qualitative analysis for clarity, ratings of distress, and psychometric analysis. Despite these differences, there is considerable evidence for content validity of all four questionnaires. Because quality of life is so poorly developed as a theoretical construct, the demonstrable

statement that all 4 questionnaires have construct validity provides little information about the questionnaires.

[13] Maille, A.R., et al. "The development of the 'Quality-of-Life for Respiratory Illness Questionnaire (QOL-RIQ)': A disease-specific quality-of-life questionnaire for patients with mild to moderate chronic non-specific lung disease." *Respiratory Medicine*, 1997, 91, 297-309.

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Measures

A uni-dimensional QOL questionnaire was constructed consisting of 55 items divided into seven domain subscales: breathing problems, physical problems, emotions, situations triggering or enhancing breathing problems, general activities, daily and domestic activities, and social activities, relationships and sexuality.

Abstract

Chronic non-specific lung disease (CNSLD) encompasses asthma as well as chronic obstructive pulmonary disease (COPD). Recently in health care, there has been increasing awareness in the functional, psychological and social aspects of the health of patients; their quality of life (QOL). Quality-of-life research addressing CNSLD patients has been rather underdeveloped for a long period of time. Recently, however, the importance of QOL is being increasingly recognized, and several research groups have started to study QOL in CNSLD patients in more detail. This paper describes the construction of a disease-specific QOL instrument for patients with mild to moderately severe CNSLD. Items relating to several domains of QOL were listed, and 171 CNSLD patients in general practice were asked how much of a problem each item had been (assessed on a seven-point Likert scale).

After applying an item-selection procedure, a uni-dimensional QOL questionnaire was constructed consisting of 55 items divided into seven domain subscales: breathing problems, physical problems, emotions, situations triggering or enhancing breathing problems,

general activities, daily and domestic activities, and social activities, relationships and sexuality. Reliability estimates of the domain subscales of the constructed questionnaire varied from 0.68 to 0.89, and was 0.92 for the QOL for Respiratory Illness Questionnaire (QOL-RIQ) total scale. A first impression of the construct validity of the questionnaire was gained by investigation of the relationship between the QOL domain subscales and several indicators of illness severity, as well as the relative contribution of illness severity variables, background characteristics and symptoms to QOL, using regression analysis. Further research to validate the questionnaire to a greater extent (construct validity, test-retest reliability and responsiveness to change) is currently taking place.

Back (6)

[1] Patrick DL, et al. "Assessing health-related quality of life in patients with sciatica." *Spine*, 1995, 20:1899-1909.

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Not available

Measures

Health-related quality-of-life measures included symptoms (frequency and bothersomeness of pain and sciatica) functional status and well-being (modified back pain-specific Roland scale and Medical Outcomes Study 36-item Short Form Health Survey (SF-36)), and disability (bed rest, work loss, and restricted activity days).

This study analyzed health-related quality-of-life measures and other clinical and questionnaire data obtained from the Maine Lumbar Spine Study, a prospective cohort study of persons with low back problems. For persons with sciatica, back pain-specific and general measures of health-related quality-of-life were compared with regard to internal consistency, construct validity, reproducibility, and responsiveness in detecting small changes over a 3-month period.

Data were collected from 427 participants with sciatica. Baseline in-person interviews were conducted with surgical and medical patients before treatment and by mail at 3 months. Health-related quality-of-life measures included symptoms (frequency and bothersomeness of pain and sciatica) functional status and well-being (modified back pain-specific Roland scale and Medical Outcomes Study 36-item Short Form Health Survey (SF-36), and disability (bed rest, work loss, and restricted activity days).

Internal consistency of measures was high. Reproducibility was moderate, as expected after a 3month interval. The SF-36 bodily pain item and the modified Roland measure demonstrated the greatest amount of change and were the most highly associated with self-rated improvement. The specific and generic measures changed in the expected direction, except for general health perceptions, which declined slightly. A high correlation between clinical findings or symptoms and the modified Roland measure, SF-36, and disability days indicated a high degree of construct validity.

These measures performed well in measuring the health-related quality-of-life of patients with sciatica. The modified Roland and the physical dimension of the SF-36 were the measures most responsive to change over time, suggesting their use in prospective evaluation. Disability day measures, although valuable for assessing the societal impact of dysfunction, were less responsive to changes over this short-term follow-up of 3 months.

[2] Claiborne, N., et al. "Measuring quality of life in back patients: Comparison of health status questionnaire 2.0 and quality of life inventory." *Social Work in Health Care*, 1999, 28, 77-95.

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QOLM Back Claiborne 1999.pdf

Measures

Health Status Questionnaire (HSQ) 2.0, the Quality of Life Inventory (QOLI)

Abstract

This paper is a reliability and validity test of the Health Status Questionnaire (HSQ) 2.0. In addition, the Quality of Life Inventory (QOLI) is compared with the HSQ 2.0 to assess concurrent validity. The study is unique because these instruments are assessed for the first time using a sample of chronic back patients. Practitioners will therefore now be able to evaluate important quality of life issues and treatment changes in this population. The HSQ 2.0 was generally found to be valid for these patients. However, two scale domains were not differentiated due to unique characteristics of spinal disease patients. The QOLI, due to the limitation of measuring only psychological well-being, did not measure problems specific to back patients.

[3] Constant, F., et al. "Use of spa therapy to improve the quality of life of chronic low back pain patients." *Medical Care*, 1998, 36 (9), 1309-1314.

File

QOLM Back Constant 1998.doc

Measures

Duke Health Profile

Abstract:

This study assessed the effectiveness of adding spa therapy to usual drug treatment in chronic low back pain patients. A total of 224 patients were assigned randomly to either a treatment (n= 128) or a control (n = 96) group. Subjects in both groups received usual drug therapy. Those in the treatment group also underwent spa therapy in Vittel, France, for 6 days a week for 3 consecutive weeks. Effectiveness was assessed using a quality-of-life scale (the Duke Health Profile), clinical measures, and the Roland and Morris disability questionnaire. Groups were compared using an analysis of variance with repeated measures.

At both 3 weeks and 3 months, patients in the treatment group exhibited significant improvement in measures of: physical and mental dimensions of quality of life, anxiety, depression, pain duration,

pain intensity, and functional disability. This study suggests that spa therapy is an effective treatment for chronic low back pain patients.

[4] Carmody, T.P. "Psychosocial subgroups, coping, and chronic low-back pain." *Journal of Clinical Psychology in Medical Settings* 2001, 8 (3), 137-148.

File

Not available

Measures

The Multidimensional Pain Inventory (MPI) was used to classify 67 chronic low-back pain (CLBP) patients into the following psychosocial subgroups: Dysfunctional, Interpersonally Distressed, Adaptive Coping, and Anomalous

Abstract

The purpose of this study was to compare psychosocial subgroups in terms of pain coping strategies, pain severity, physical impairment, pain behavior, affective distress, and response to pain management treatment. The Multidimensional Pain Inventory (MPI) was used to classify 67 chronic low-back pain (CLBP) patients into the following psychosocial subgroups: Dysfunctional, Interpersonally Distressed, Adaptive Coping, and Anomalous.

These MPI subgroups were compared on the Pain Behavior Checklist, Behavioral Observation Measure of Pain Behavior, Revised Coping Strategies Questionnaire, and Chronic Disease Index. The Dysfunctional subgroup reported significantly more pain behavior, disability, affective distress, and catastrophizing than either the Interpersonally Distressed subgroup or Adaptive Copers, but was not significantly different on measures of adaptive coping strategies. The percentage of dropouts from treatment was significantly less among Adaptive Copers (11 percent) than among the Dysfunctional (33 percent) or Interpersonally Distressed (47 percent) subgroups. Differences in affective distress found among the MPI subgroups at baseline were not evident at the post treatment assessment. The present findings support the use of MPI psychosocial subgroup analysis

to enhance our understanding of differential response to chronic pain and pain management intervention.

[5] Claiborne, N., et al. "Measuring quality of life changes in individuals with chronic low back conditions: A back education program evaluation." *Evaluation and Program Planning* 2002, 25 (1), 61-70.

File

Not available

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36) physical and mental component summary scores

This study examined the effectiveness of an interdisciplinary back evaluation and education program in improving patient health-related quality of life utilizing the SF-36 physical and mental component summary scores as dependent variables. It used repeated measures analysis of covariance (ANCOVA) in a pre-post design to examine a back program group of patients (N=92) over a period of one year. This was compared to an ANCOVA pre-post design examining a physician clinic group of back patients (N=61) over one year. Control variables for each group included age, gender, payor, major depression risk, back pain level, disability scale, and whether surgery occurred. Because of selection bias, the two groups could not be compared, although a qualitative comparison suggests that the back program group had an effect independent of physician visits and time.

The back education program was probably effective in improving patients' physical quality of life. Diminished disability, being male, having had surgery during treatment, not receiving workers' compensation, and not being at risk for major depression at baseline helped improve physical component summary scores. Treatment had no effect on mental component summary scores. The comparison group, which received no treatment, did not statistically improve in either the physical or mental component/domain.

[6] Ernst, M.E., et al. "Drug-related problems and quality of life in arthritis and low back pain sufferers." *Value in Health*, 2003, 6 (1), 51-58.

File

QOLM Back Ernst 2003.pdf

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The objective of this study was to determine the relationship between drug-related problems (DRPs) and health-related quality-of-life (HRQoL) in ambulatory, community-dwelling patients with musculoskeletal disorders. A 12-month, prospective, observational study was conducted in 12 independent community pharmacies in eastern Iowa. Ambulatory patients with self-reported diagnoses of osteoarthritis, rheumatoid arthritis, or low back pain were invited to participate. During quarterly visits to the pharmacy, patients used touch-screen computers to fill out the Short Form-36 (SF-36) general health survey. Using the results of these point-of-service health status assessments, community pharmacists interviewed patients to assess for DRPs.

To examine the influences of different DRP characteristics on HRQoL and controlling for potential confounders, both univariate and multivariate analyses were performed using the change in physical component summary (PCS) score and mental component summary (MCS) score of the SF-36 from baseline to 12 months as the dependent variables. In each regression, the independent variables were those significant variables from the univariate analyses, as well as the types of DRPs and their outcomes. Results: A total of 461 patients were enrolled in the study. Through 12 months, 926 cumulative DRPs were identified.

Overall regression models were significant for the PCS and MCS scores, respectively. Two types of DRPs showed significant negative associations with change in PCS: wrong drug and needs additional drug therapy. One type of DRP showed significant negative associa-

tion with change in MCS: needs additional drug therapy. Resolution or improvement in DRPs showed a significant positive correlation with change in MCS but not PCS. Two DRPs, needs additional drug therapy and wrong drug, were associated with reduced self-reported physical health in arthritis and low back pain.

Arthritis (10)

[1] Singh JA, et al. "Health-Related Quality of Life Predicts Future Health Care Utilization and Mortality in Veterans with Self-Reported Physician-Diagnosed Arthritis: The Veterans Arthritis Quality of Life Study." *Semin Arthritis Rheum*, 2005, 34(5):755-65.

File

Not available

Measures

SF-36V (modified from Medical Outcomes Study Short Form 36-items Health Survey (SF-36) for use in veterans) and questions regarding demographics, current smoking status, limitation of activities of daily living (ADLs), and preexisting physician-diagnosed medical conditions, including arthritis

Abstract

To investigate whether health-related quality of life (HRQOL) measures predict health care utilization and mortality in a cohort of veterans with self-reported physician-diagnosed arthritis.

A cohort of veterans from the Upper Midwest Veterans Integrated Service Network (VISN) was mailed a self-administered questionnaire that was composed of the SF-36V (modified from SF-36 for use in veterans) and questions regarding demographics, current smoking status, limitation of activities of daily living (ADLs), and preexisting physician-diagnosed medical conditions, including arthritis. Within subjects reporting physician-diagnosed arthritis, the study team analyzed the associations between the SF-36V component summary scales (physical and mental component summary, PCS and MCS, respectively) and the occurrence of any hospitalization,

number of hospitalizations, number of outpatient visits, and mortality, for the year after survey administration, using multivariable regression analyses.

Of 34,440 survey responders who answered a question regarding arthritis, 18,464 (58 percent) subjects reported physician-diagnosed arthritis. Arthritic patients in the lowest tertile of PCS scores had significantly higher odds of any hospitalization (Odds ratio (OR) 1.49, 95 percent confidence interval (CI) [1.25-1.76]) and mortality (OR 1.69, 95 percent CI [1.18-2.42]), and a significantly higher number of hospitalizations/year (Rate ratio (RR) 1.09, 95 percent CI [1.05-1.13]) and outpatient visits/year (RR 1.07, 95 percent CI [1.03-1.11]). Arthritic patients in the lowest tertile of MCS scores had significantly higher odds of any hospitalization (OR 1.20, 95 percent CI [1.02-1.41]), mortality (OR 2.14, 95 percent CI [1.56-2.94]), and a significantly higher number of hospitalizations/year (RR 1.05, 95 percent CI [1.02-1.09]) and outpatient visits/year (RR 1.07, 95 percent CI [1.03-1.11]).

HRQOL, as assessed by the SF-36V, predicts future inpatient and outpatient health care utilization and mortality in veterans with self-report of physician-diagnosed arthritis.

[2] Sheasby, J.E., et al. "Psychometric properties of the Rosenberg Self-Esteem Scale among people with Arthritis." *Psychological Reports*, 2000, 86, 1139-1147.

File

Not available

Measures

Rosenberg Self-Esteem Scale

Abstract

Explores the psychometric properties of the Rosenberg Self-esteem Scale among arthritic adults and undergraduate students in England. Use of the structural equation modeling to examine dimen-

sionality of the scale; Account on the model fit statistics for the Rosenberg scale; Comparison of factor structures of the scale between arthritic adults and students.

[3] Barlow, J.H., et al. "Educational preferences, psychological well-being and self-efficacy among people with rheumatoid Arthritis." *Patient*, 2002.

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QOLM Arthritis Barlow 2002.pdf

Measures

Psychological well-being

Abstract

The need for implementing a holistic approach to patient care is widely accepted. In order to improve the services offered, a series of studies investigating the needs of one group of patients attending a regional hospital have been initiated. An earlier study investigated the psychological well-being and educational needs of people with rheumatoid arthritis (RA) attending the outpatient clinics.

Results showed that the need for information, education and advice was similar, regardless of disease duration or severity and encompassed the following topic areas: understanding RA and its treatment; management of pain and fatigue; coping with 'flares'; aids and adaptations; impact on work, family, relationships, and emotions. Similarly, psychological well-being was independent of disease duration with 48 percent at risk of clinically anxious mood and 32 percent at risk for clinically depressed mood. Illness acceptance beliefs were identified as significant predictors of both anxiety and depression.

These findings support the need for interventions incorporating emotional support, counseling and education about RA. The purpose of the follow-up study reported here was to examine patients' preferences for psycho-educational interventions that could be offered to better meet their needs. In addition, the correlates of psy-

chological well-being that might be amenable to change through psycho-educational interventions were further investigated.

[4] Jakobsson, U. and I.R. Hallberg. "Pain and quality of life among older people with rheumatoid Arthritis and/or osteo Arthritis: A literature review." *Journal of Clinical Nursing* 2002, 11 (4), 430-443.

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QOLM Arthritis Jakobsson 2002.pdf

Measures

Literature review

Abstract

The aim of this study was to review the research literature on pain and quality of life (QoL) and the relationship between these variables among people aged 75 years and above with rheumatoid arthritis and/or osteoarthritis. A Medline and CINAHL search was carried out using MeSH terms rheumatoid arthritis, osteoarthritis, QoL and pain in various combinations. Seventeen articles were identified that met the requirements for methodological quality and inclusion criteria. No study focused only on respondents aged 75 years or over. The studies had varying representation of this age group.

Pain was common in both groups and was found to increase with age and disease duration among those with rheumatoid arthritis but not among those with osteoarthritis. Increased pain could lead to depression. Pain, functional limitation and increased age were found to decrease QoL among those with rheumatoid arthritis and osteoarthritis alike. Social support was found to buffer against negative effects on QoL among those with osteoarthritis while no moderating effects were found in rheumatoid arthritis. Increased age was found to relate to pain (rheumatoid arthritis) and decrease QoL (both rheumatoid arthritis and osteoarthritis).

It is, however, hard to draw any firm conclusions about older people's pain and QoL because of the lack of studies including respon-

dents aged 75 years or over. Thus, research about pain and QoL, especially focusing on the old and the very elderly with rheumatoid arthritis/osteoarthritis, is needed. It also seems justified to say that *nursing* care should especially focus on older people and that these people should be assessed for their level of pain, functional limitations and QoL especially in the case of having rheumatoid arthritis and/or osteoarthritis.

[5] Potter, P.T., et al. "Interpersonal workplace stressors and well-being: A multi-wave study of employees with and without Arthritis." *Journal of Applied Psychology*, 2002, 87 (4), 789-796.

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Measures

Well-being

Abstract

The within-person influence of interpersonal stressors on affective well-being and physical well-being was investigated for 109 women with and without arthritis. Participants were interviewed on a weekly basis for 12 consecutive weeks, and the prospective data were analyzed by using hierarchical linear modeling.

Overall, interpersonal workplace stressors independently predicted both well-being outcomes. Interpersonal stressors outside the workplace were related to negative affect but not to arthritis symptoms. Compared with healthy controls, arthritis patients' ratings of negative affect were equally reactive to workplace stressors. Neuroticism did not moderate stressor reactivity for either dependent variable but did predict mean levels of negative affect. The data support the hypothesis that the psychosocial environment of the workplace contributes unique effects on well-being.

[6] Rejeski, W.J., et al. " Perceived importance and satisfaction with physical function in patients with knee osteoArthritis." *Annals of Behavioral Medicine*, 1998, 20 (2), 141.

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Not found

Measures

Measures assessed satisfaction with function for six physical activities)

Abstract

This investigation examined the determinants of satisfaction with physical function for participants in an Observational Arthritis Study in Seniors (OASIS). The sample consisted of 480 men (51 percent) and women (49 percent) over the age of 65 years who had difficulty performing activities of daily living due to knee pain. As part of baseline testing for OASIS, participants completed a measure that assessed satisfaction with function for six physical activities. After controlling for relevant covariates, scores on the satisfaction index were regressed on seven conceptually relevant predictor variables.

The results revealed that satisfaction with physical function is a distinct construct from level of function, irrespective of whether the latter variable is measured objectively or subjectively. When entered into a hierarchical regression model, 6-minute walk test data accounted for 11 percent of the variance in satisfaction scores, whereas perceived difficulty accounted for an additional 22 percent. Moreover, a significant interaction term between importance and perceived difficulty revealed that patients who rated the activities as important and who had high levels of perceived difficulty had the lowest satisfaction scores. Discussion focuses on the determinants of satisfaction with physical function with emphasis on the interaction between perceived difficulty and importance.

[7] Meehan, R., et.al. "The stability of health status in rheumatoid Arthritis: A five year study of patients with established disease." *American Journal of Public Health*, 1988, 78, 1484-1487.

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Measures

Arthritis Impact Measurement Scales (AIMS))

Abstract

The authors employed a health status measure to describe the outcomes of rheumatoid arthritis patients over five years. Of the 410 rheumatoid arthritis patients who were originally administered the Arthritis Impact Measurement Scales (AIMS), 299 completed a follow-up five years later.

Data were analyzed using nine health status scales, three components of health status, and an overall arthritis impact item. Results for survivors indicated that there were no clinically important deteriorations in any of these measures. In fact, small improvements on most measures were found. The health status changes were similar for patients originally in a clinical trial and for those receiving routine specialty care. Age was found to positively relate to improvements in psychological status and overall arthritis impact, but the study was unable to demonstrate any consistent effects of sex, marital status, education, or disease duration.

Our results contrast with other studies that have noted major declines over time in the health status of patients with rheumatoid arthritis. Furthermore, level of education was not a major determinant of morbidity in this group. These results suggest that health status in certain patients with rheumatoid arthritis is more stable than previously thought. This has implications for both clinical practice and clinical research in rheumatology.

[8] Lubeck, D.P. "Health-related quality of life measurements and studies in rheumatoid Arthritis." *American Journal of Managed Care*, 2002, 8 (9), 811-821.

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QOLM Arthritis Lubeck 2002.pdf

Measures

SF-36V (modified from SF-36 for use in veterans) and questions regarding demographics, current smoking status, limitation of activities of daily living (ADLs), and preexisting physician-diagnosed medical conditions, including arthritis

Abstract

Rheumatoid arthritis (RA) is a major cause of disability and impairment of health-related quality of life (HRQOL) in the United States. Increasingly, HRQOL assessments are becoming part of a package of materials reviewed by managed care providers in making formulary and reimbursement decisions. To help managed care administrators understand how to interpret and apply the results of HRQOL assessment scales, several patient-reported instruments in common use in RA were reviewed, including the Health Assessment Questionnaire (HAQ), Modified HAQ, Arthritis Impact Measurement Scale, and the 36-item Short-Form Health Survey.

These self-assessment scales help improve patient/physician communication and thus enable better treatment decision-making. The scales can also aid managed care administrators in evaluating the efficacy and the financial benefits of therapies. The HAQ was one scale that stood out as being short, easy to administer, and disease-specific for RA.

Self-assessment reports, such as the HAQ, provide key data on disability and HRQOL from the patient's perspective. The information so gained enables the clinician to select the most cost-effective therapies and interventions that slow disease progression, maintain functional status, and improve HRQOL.

[9] Kaplan, R.M., et al. "Comparison of measured utility scores and imputed scores from the SF-36 in patients with rheumatoid Arthritis." *Medical Care*, 2005, 43(1), 79-87.

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QOLM Arthritis Kaplan 2005.pdf

Measures

HUI-2, HUI3, EQ-5D, and the disease-specific HAQ

Abstract

The authors sought to evaluate 3 methods for imputing utility-based outcomes from clinical trial data measured using the Medical Outcomes Study 36-Item Short Form (SF-36). The subjects included 131 male and 505 female adults (mean age, 55.42 +/- 12.59 years) who were participating in a randomized clinical trial evaluating a new treatment of adults with rheumatoid arthritis (RA).

All 4 imputed scores were significantly correlated with HUI2, HUI3, EQ-5D, and the disease-specific HAQ scores at baseline and at the end of the clinical trial period ($P < 0.05$). Changes in the imputed scores from baseline to end of study also were significantly correlated with corresponding changes in the measured utility scores and the HAQ score ($P < 0.0001$). For all imputed and measured scores, changes from baseline were associated with the clinical assessments, ACR20 and ACR50. The associations were stronger for the utility-based measures than the imputed indices. Both imputed and measured scores were sensitive to change in the clinical trial. However, mean scores for the HUI3 and the Brazier VAS were significantly lower than for the other measures.

Imputed utility-based score estimates are significantly correlated with measured utility outcomes. However, the imputed measures had more constrained variability, showed poorer correspondence to the ACR20 and ACR50 benchmarks, and predicted less than half of the variance in actual utility-based outcomes. Therefore, directly assessed, not imputed, utility-based measures should continue to be favored for cost-effectiveness analysis.

[10] Abell, J.E., et al. "Physical activity and health related quality of life among people with Arthritis." *Journal of Epidemiological and Community Health*, 2005, 59(5), 380-385.

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QOLM Arthritis Abell 2005.pdf

Measures

HRQOL was estimated using the number of physically or mentally unhealthy days during the past 30 days

Abstract

To assess the association between physical activity and health related quality of life (HRQOL) among persons with arthritis or chronic joint symptoms (CJS). The study used a cross sectional survey to investigate the relation between physical activity level and HRQOL. HRQOL was estimated using the number of physically or mentally unhealthy days during the past 30 days. Physical activity was categorized as recommended, insufficient, or inactive according to federal activity recommendations. Persons with arthritis were defined as those with either self reported CJS or doctor diagnosed arthritis. The sample consisted of US adults residing in all 50 states and the District of Columbia. Participants: Respondents (n =212 000) in the 2001 behavioral risk factor surveillance system (BRFSS), an annual population based, telephone survey.

The 33 percent of BRFSS respondents with arthritis had a mean of 6.7 physically and 4.9 mentally unhealthy days during the past 30 days, compared with 1.8 and 2.7 among those without arthritis. Inactive men and women were 1.2-2.4 times more likely to report impaired HRQOL compared with those who met physical activity recommendations. Men and women who engage in insufficient physical activity also report variably reduced HRQOL.

Among people with arthritis, recommended levels of physical activity were associated with fewer mean physically and mentally unhealthy days and a decreased probability of having severely impaired physical or mental HRQOL.

Neurological (2)

[1] Murrell, R.C., et al. "Assessing quality of life in persons with severe neurological disability associated with multiple sclerosis: The psychometric evaluation of two quality of life measures." *British Journal of Health Psychology*, 1999, 4, 349-363.

File

Not available

Measures

SEIQoL-DW (a person-centred measure) and the Medical Outcomes Study Short Form 36-items Health Survey (SF-36) (a health-based measure)

Abstract

The purpose of this study was to examine the psychometric properties of two conceptually different quality of life (QoL) measures, the SEIQoL-DW (a person-centred measure) and the SF36 (a health-based measure), in a severely disabled population of individuals with multiple sclerosis (MS). A factorial repeated measures design was used. The two QoL measures were administered at baseline to 30 individuals with MS at the Royal Hospital for Neuro-disability, Putney; participants were aged between 20 and 65 years and selected on the basis of their communication ability, years since diagnosis and extent of physical disability (using EDSS ratings). Administration of the SEIQoL-DW and the SF-36 was repeated on five fortnightly occasions on a subset of 22 participants 10 months after baseline. On each of the five re-test occasions, participants also rated their QoL 'today' and 'generally' on visual analogue scales, and reported significant positive/negative life changes that had affected their QoL.

The SF-36 was more reliable by traditional re-test standards than the SEIQoL-DW, but several floor and ceiling effects were observed. Only the SEIQoL-DW was significantly related to QoL today (average correlation 0.52) and QoL generally (average correlation 0.52) ($p < .05$) ratings and analyses using ANOVA suggested that the measure

was also more sensitive to life changes reported ($F(2, 36) = 7.57, p < .01$).

The SEIQoL-DW is recommended as a suitable person-centred measure for use with the current population, because it appears to have good face validity and is capable of reflecting individual reports of life change between assessments. It has potential use in other severely disabled samples who obtain low scores on health-based measures because of their physical status, providing a more holistic view of individual QoL than the SF-36.

[2] Nordeson, A., et al. "Self-reported quality of life for patients with progressive neurological diseases." *Quality of Life Research*, 7 1998, (3), 257-266.

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Measures

Quality of Life: status and change (QLsc.)

Abstract

Progressive neurological diseases influence the life situation of patients either totally or partially. Such patients' own ratings of their life situation and well-being were made using a health-related quality of life HRQoL instrument called Quality of Life: status and change (QLsc). In general the interviewees rated their life domains in terms of positive response alternatives and no subgroups were found, e.g. with the same diagnoses, periods of sickness or age. The results suggest that the interviewees' experience of quality of life (QoL) is subjective and individual. The interviewees who had been to the rehabilitation centre several times rated their quality of life, in terms of positive response alternatives for the items covering overall experiences of bodily health, well-being and their whole life as well as for items in the social domain, to a greater extent than those who were visiting it for the first time.

Endocrine (2)

[1] Sonino, N., et al. "Psychological distress and quality of life in endocrine disease." *Psychotherapy and Psychosomatics*, 1990, 54, 140-144.

File

Not available

Measures

Four questionnaires were used: the Hospital Anxiety and Depression Scale (HADS), the Impact of Event Scale (IES), the Life Orientation Test (LOT) and the Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

To study quality of life among patients living with a hereditary tumor syndrome, the small group with multiple endocrine neoplasia type 1 (MEN1) was selected. It is characterized by multifocal adenomas of the pancreas, parathyroid, anterior pituitary and other endocrine glands. Patients were assessed at an in-hospital stay and six months later at home. Patients at a specialist ward for MEN1 were recruited consecutively (n = 36) during one year. Eighty-one percent participated (n = 29). Four questionnaires were used: the Hospital Anxiety and Depression Scale (HADS), the Impact of Event Scale (IES), the Life Orientation Test (LOT) and the Short Form-36 (SF-36).

Psychosocial outcome measures (anxiety, depression, intrusion, avoidance) changed only marginally between the in-hospital stay and six months later at home. However, depression increased for patients categorized as having a high burden of disease and treatment. Compared to population-based norm values, the SF-36 scores of the patient group MEN1 were lower for General Health and Social Functioning. Optimism assessed at the hospital was a predictor of Mental Health six months later. Most MEN 1 patients (70 percent) were pessimists. Patients having a higher burden of disease and treatment are in need of support after discharge. Patients could

easily be monitored with questionnaires and, when indicated, offered help for their psychosocial distress.

[2] Larsson, G., et al. "Health-related Quality of Life in Patients with Endocrine Tumours of the Gastrointestinal Tract." *Acta Oncologica* Vol. 38, No. 4, pp. 481-490, 1999

File

QOLM end larson 99.pdf

Measures

Health-related quality of life (HRQOL) (EORTC QLQ-C30)

Abstract

Health-related quality of life (HRQOL) (EORTC QLQ-C30) and levels of anxiety and depression (HADS) were investigated in patients with endocrine tumours of the gastrointestinal tract treated with interferon and/or a somatostatin analogue. In addition, patient perceptions of the importance of and satisfaction with some HRQOL aspects were studied. QOL was perceived as quite good, but more than half of the patients reported diarrhoea. The levels of anxiety and depression were low. Patients perceived physical HRQOL aspects as most important for a good QOL and stated the highest satisfaction with some social aspects. Patients who reported high levels of anxiety or depression were less satisfied with several HRQOL aspects, had more health problems, and a lower level of functioning on several of the EORTC QLQ-C30 scales and single items. Neither demographic nor medical background variables seemed to have an influence on the results. The relatively high QOL could be explained by the fact that most patients had had their treatment for a long period and thus had time to adjust to the situation.

Visual (2)

[1] Lee, P., et al. "The relationship between visual acuity and functioning and well-being among diabetics." *Quality of Life Research*, 1995, 4 (4), 319-324.

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Not available

Measures

SF-36

Given the enormous recent interest in functional capabilities related to vision, the goal of this study was to examine the relationship of standard clinical measures of vision (e.g. Snellen acuity) to functioning and well-being. The association between Snellen visual acuity, Amsler grid distortion and presence of diabetic retinopathy with self-reported functioning and well-being (SF-36) were examined in a sample of 327 diabetics from the Medical Outcomes Study (MOS). There was little or no correlation between Snellen visual acuity, Amsler grid distortion or diabetic retinopathy and functioning and well-being (i.e. SF-36 scales).

Maximum product-moment correlation was 0.15 with worst eye visual acuity, 0.13 with best eye visual acuity, 0.08 with presence of retinopathy, and 0.10 with Amsler grid distortion. Analysis of variance revealed that visual acuity (both best and worst eye) was statistically related only to the physical function scale; no other exam measure was related to any other SF-36 scale score. Snellen visual acuity, Amsler distortion and diabetic retinopathy correlate weakly with patient self-reported functioning and well-being. Thus, the information provided by functioning and well-being measures is complementary to that of standard clinical measures of visual ability.

[2] de Boer MR, et al. "Evaluation of Cross-sectional and Longitudinal Construct Validity of Two Vision-related Quality of Life Questionnaires: The LVQOL and VCM1." *Qual Life Res*, March 2006, 15(2):233-48.

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Measures

Low Vision Quality of Life (LVQOL) questionnaire and the Vision-related Quality of Life Core Measure (VCM1)

Abstract

The Low Vision Quality of Life (LVQOL) questionnaire and the Vision-related Quality of Life Core Measure (VCM1) are two of the many vision-related quality of life (QOL) questionnaires that have been developed in recent years. Although psychometric properties of the LVQOL and VCM1 compare well with other vision-related QOL questionnaires, construct and longitudinal validity have not been assessed (adequately). The purpose of this study was to examine the cross-sectional and longitudinal construct validity of these questionnaires by testing specific pre-specified hypotheses about the relations of these questionnaires with other measures. The percentage of hypotheses regarding the cross-sectional construct validity that were refuted for the LVQOL was 22 percent for the basic aspects of vision subscale, 50 percent for the mobility subscale, 39 percent for the adjustment subscale and 17 percent for the reading and fine work subscale. For the VCM1 this percentage was 57 percent. For the longitudinal construct validity the percentage of hypotheses that were refuted ranged from 33 to 75 percent for the LVQOL subscales and was 50 percent for the VCM1. In conclusion, cross-sectional construct validity was satisfactory for the LVQOL subscales, but seemed poor for the VCM1. In addition, the longitudinal validity of these scales was poor to moderate.

Auditory (3)

[1] Chisolm TH, et al. "The WHO-DAS II: psychometric properties in the measurement of functional health status in adults with acquired hearing loss." *Trends Amplif*, 2005, 9(3):111-26.

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Measures

World Health Organization's (WHO) Disability Assessment Scale II (WHO-DAS II), Medical Outcomes Study Short Form 36-items Health Survey (SF-36))

Abstract

The World Health Organization's (WHO) Disability Assessment Scale II (WHO-DAS II) is a generic health-status instrument firmly grounded in the WHO's International Classification of Functioning, Disability and Health (WHO-ICF). As such, it assesses functioning for six domains: communication, mobility, self-care, interpersonal, life activities, and participation. Domain scores aggregate to a total score. Because the WHO-DAS II contains questions relevant to hearing and communication, it has good face validity for use as an outcome measure for audiologic intervention.

The purpose of the present study was to determine the psychometric properties of the WHO-DAS II on a sample of individuals with adult-onset hearing loss, including convergent validity, internal consistency, and test-retest stability. Convergent validity was established by examining correlations between the WHO-DAS II (domain and total scores) and the Abbreviated Profile of Hearing Aid Benefit (APHAB) and the Hearing Aid Handicap for the Elderly (HHIE), two disease-specific measures, as well as with the Short Form-36 for veterans (SF-36V), a second generic measure. Data on all four measures were collected from 380 older individuals with adult-onset hearing loss who were not hearing aid users.

The results of the convergent validity analysis revealed that the WHODAS II communication domain score was moderately and significantly correlated with scores on the APHAB and the HHIE. WHO-DAS II interpersonal and participation domain scores and the total scores were also moderately and significantly correlated with HHIE scores. These findings support the validity of using the WHO-DAS II for assessing activity limitations and participation restrictions of adult-onset hearing loss. Several WHO-DAS II domain scores and the total score were also significantly and moderately-markedly correlated with scores from the SF-36V. These findings support the validity of the WHO-DAS II as a generic health-status instrument.

Internal consistency reliability for all the domain scores was adequate for all but the interpersonal domain.

Test-retest stability for all the domain scores was adequate. Critical difference values were calculated for use in clinical application of the WHO-DAS II. From these findings, the team concluded that the WHO-DAS II communication, participation, and total scores can be used to examine the effects of adult-onset hearing loss on functional health status. Further work examining the utility of the WHO-DAS II as an outcome measure for hearing aid intervention is warranted.

[2] Dalton, D.S., et al. "The impact of hearing loss on quality of life in older adults." *Gerontologist*, 2003, 43 (5), 661-668.

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Measures

Health-related quality of life was assessed by using measures of activities of daily living (ADLs), instrumental ADLs (IADLs) and Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The authors investigate the impact of hearing loss on quality of life in a large population of older adults. Data are from the 5-year follow-up Epidemiology of Hearing Loss Study, a population-based longitudinal study of age-related hearing impairment conducted in Beaver Dam, WI. Participants (N = 2,688) were 53–97 years old (mean = 69 years) and 42 percent were male. Difficulties with communication were assessed by using the Hearing Handicap for the Elderly—Screening version (HHIE-S), with additional questions regarding communication difficulties in specific situations.

Health-related quality of life was assessed by using measures of activities of daily living (ADLs), instrumental ADLs (IADLs) and the Short Form 36 Health Survey (SF-36). Hearing loss measured by audiometry was categorized on the basis of the pure-tone average of hearing thresholds at 0.5, 1, 2, and 4 kHz. Of participants, 28 percent had a mild hearing loss and 24 percent had a moderate to se-

vere hearing loss. Severity of hearing loss was significantly associated with having a hearing handicap and with self-reported communication difficulties. Individuals with moderate to severe hearing loss were more likely than individuals without hearing loss to have impaired ADLs and IADLs. Severity of hearing loss was significantly associated with decreased function in both the Mental Component Summary score and the Physical Component Summary score of the SF-36 as well as with six of the eight individual domain scores. Severity of hearing loss is associated with reduced quality of life in older adults.

[3] Fellingner, J., et al. "An innovative and reliable way of measuring health-related quality of life and mental distress in the deaf community." *Social Psychiatry and Psychiatric Epidemiology*, 2005, 40(3), 245.

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Measures

The Brief version of the WHO Quality of Life (WHOQOL) Questionnaire, the 12-item General Health Questionnaire (GHQ-12) and the Brief Symptom Inventory (BSI))

Abstract

Structured assessment of quality of life and mental distress in deaf people is difficult for various reasons. This paper describes the development and reliability of an interactive computer-based assessment package for measuring quality of life and psychological distress in the deaf population.

The Brief version of the WHO Quality of Life (WHOQOL) Questionnaire, the 12-item General Health Questionnaire (GHQ-12) and the Brief Symptom Inventory (BSI) had been translated into sign language and videotaped. A total of 236 members of the deaf community in Upper Austria participated by responding to a program consisting of self-administered written and videotaped test-items presented to them on a notebook computer. The reliability of the various assessments was established on this large community sample.

When reliability of the versions for the deaf was compared with that of written versions of the same measures in general population samples, it was found to be somewhat lower, although still in an acceptable range, for the WHO-QOL and the GHQ-12. For the BSI, the reliability was even higher than that of the general population.

For deaf individuals whose preferred communication is sign language, quality of life and mental distress can be effectively and reliably assessed with the use of carefully translated and adapted common instruments.

Affect on family members (9)

[1] Fyer AJ, et al. "The DSM-IV Panic Disorder Field Trial: Panic Attack Frequency and Functional Disability." *Anxiety*, 1996, 2(4):157-166.

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Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The goal of the DSM-IV panic disorder field trial was to provide an empirical basis for choosing between alternate proposals (DSM-III-R and proposed DSM-IV) for the diagnostic threshold for panic disorder, in particular the number and frequency of panic attacks required for diagnosis. The two criteria sets were compared with respect to their ability to identify individuals whose panic attacks were associated with distress, impairment, or help-seeking. Subjects were a convenience sample screened in three geographically diverse primary care clinics for presence (past 6 months) or absence (lifetime) of panic attacks. Each underwent a clinician-administered semi-structured interview which included assessment of panic frequency, panic-related impairment, psychiatric diagnosis, health services utilization, and medical illness. Self-perceived health-related quality of life was assessed using the Medical Outcome Study SF-36

Health Survey Questionnaire. Although both proposals diagnosed the same proportion of panic-impaired individuals, they were not completely overlapping. Twenty percent of subjects diagnosed by each criteria set were excluded by the other. Subjects who had been excluded by the DSM-III-R but included by the DSM-IV proposal were those with fewer than 4 attacks in 4 weeks who also denied worry about the "next" attack.

Broadening the worry criterion to include concerns about the health implications of attacks enabled diagnosis of this group. Subjects who met DSM-III-R, but not the proposed DSM-IV criteria, had 4 attacks in 4 weeks but denied any panic related worry. Modification of the DSM-IV proposal to include a month of worry or "a significant change in behavior related to the attacks" allowed inclusion of this group in the diagnostic category. These data suggest that the finalized DSM-IV panic disorder criteria will diagnose a greater proportion of individuals whose panic attacks are associated with impairment without inflating the diagnostic category or significantly reducing specificity.

[2] Riggs DS, et al. "The Quality of the Intimate Relationships of Male Vietnam War Veterans: Problems Associated with Posttraumatic Stress Disorder." *Journal of Traumatic Stress*, 1998, 11(1):87-101.

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Measures

Quality of intimate relations

Abstract

This study examined the quality of the intimate relationships of male Vietnam veterans. Heterosexual couples in which the veteran had posttraumatic stress disorder (PTSD; n = 26) were compared to couples in which the veteran did not have PTSD (n = 24). Over 70 percent of the PTSD veterans and their partners reported clinically significant levels of relationship distress compared to only about 30 percent of the non-PTSD couples. Relationship difficulties appeared

to encompass a wide range of areas, with PTSD veterans and their partners reporting that they had more problems in their relationships, more difficulties with intimacy, and had taken more steps toward separation and divorce than the non-PTSD veterans and their partners. The degree of relationship distress was correlated with the severity of veterans' PTSD symptoms, particularly symptoms of emotional numbing. Research and clinical implications of the results are discussed.

[3] Ruscio AM, et al. "Male War-Zone Veterans' Perceived Relationships with Their Children: The Importance of Emotional Numbing." *J Trauma Stress*, 2002, 15(5):351-7.

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Measures

Perceived quality of all relationship domains

Abstract

Despite growing recognition of substantial interpersonal impairment among many war-zone veterans with posttraumatic stress disorder (PTSD), little is known about the association between PTSD symptomatology and veterans' relationships with their children. This study examined the differential pattern of associations between the symptom clusters of PTSD and the perceived father-child relationships of 66 male Vietnam veterans. Analyses revealed that only the emotional numbing cluster was significantly related to perceived quality of all relationship domains. The association between emotional numbing and perceived relationship quality remained significant in regression analyses even after controlling for fathers' family-of-origin stressors, combat exposure, depression, and substance abuse. Findings suggest that emotional numbing may be the component of PTSD most closely linked to interpersonal impairment in war-zone veterans.

[4] Taft CT, et al. "Partners' Ratings of Combat Veterans' PTSD Symptomatology." *J Trauma Stress*, 1999, 12(2):327-34.

File

QOLM Affect on family Taft 1999.pdf

Measures

Marital relationship quality measurements and M-PTSD scores

Abstract

The study design was to compare veteran self-report scores on the M-PTSD with scores completed by spousal partners and to examine the impact of marital relationship quality on M-PTSD score concordance. SAMPLE: 466 veteran-partner dyads from the National Vietnam Veterans Readjustment Study (NVVRS). 376 were male veterans and their female partners (47 percent white/other veterans, with 55 percent white/other spouses); the remaining 90 were female veterans and their male partners (virtually 100 percent white/other). The majority of all pairs (78.3 percent) had one or more children in the home. 32 percent of included veterans had a low risk PTSD profile and formed a control group, while 31 percent had a high probability of PTSD and 37 percent were below PTSD cutoff score but with significant combat exposure (21 percent) or were below cutoff score with non-specific stress (16 percent).

Archival data including marital relationship quality measurements and MPTSD scores were obtained from the NVVRS. The parallel version of the M-PTSD given to partners had slight changes in instructions and wording. Symptom reporting by veterans and their partners agreed moderately. There was little evidence that marital relationship quality impacted score concordance.

[5] Cook JM, et al. "Posttraumatic Stress Disorder and Current Relationship Functioning among World War II Ex-Prisoners of War." *Journal of Family Psychology*, 2004, 18(1):36-45.

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Measures

Quality of intimate relationships

Abstract

This study examined the association of posttraumatic stress disorder (PTSD) with the quality of intimate relationships among present-day male World War II ex-prisoners of war (POWs). Ex-POWs had considerable marital stability; those with PTSD were no less likely to be in an intimate relationship. Ex-POWs in an intimate relationship who had PTSD (N=125) were compared with ex-POWs in a relationship who did not have PTSD (N=206). Marital functioning was within a range expected for persons without traumatic exposure. Yet, over 30 percent of those with PTSD reported relationship problems compared with only 11 percent of those without PTSD. Ex-POWs with PTSD reported poorer adjustment and communication with their partners and more difficulties with intimacy. Emotional numbing was significantly associated with relationship difficulties independent of other symptom complexes and severity of PTSD. Implications for clinical practice are discussed.

[6] Baumgarten, M., et al. "The psychological and physical health of family members caring for an elderly person with dementia." *Journal of Clinical Epidemiology*, 1992, 45, 61-70.

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Measures

Interview from close family members of dementia patients (CGs), and from a comparison group made up of close family members of patients undergoing cataract surgery (non-caregivers, NCGs)

Abstract

Most elderly persons with dementia are cared for at home, usually by the spouse or an adult child. The objective of the present study was to determine whether there is an excess of psychological and physical health problems among family caregivers (CGs) of elderly

persons with dementia. Data were obtained by interview from close family members of dementia patients (CGs), and from a comparison group made up of close family members of patients undergoing cataract surgery (non-caregivers, NCGs). CGs had significantly higher levels of depression and physical symptoms than NCGs. The association between caregiving and the health variables was stronger among subjects who were the patient's spouse than among those who were the patient's child. Furthermore, greater behavioral disturbance in the demented patient was associated with higher levels of morbidity in the CG. The results suggest that CGs might benefit from careful monitoring of their health status, and from greater access to specialized support services.

[7] Lieberman, M.A. and L. Fisher. "The impact of chronic illness on the health and well-being of family members." *The Gerontologist*, 1995, 35, 94-102.

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Measures

Family member health and well-being

Abstract

Examined is the impact of dementia on the physical and mental health of all family members caring for an ill parent/spouse. The sample included 97 spouses of patients diagnosed with either Alzheimer's disease or vascular dementia, 186 offspring, and 97 offspring spouses or "in-laws." Multivariable regression tested the association between severity of the illness and family member health and well-being. Severity was significantly associated with health and well-being for spouses, offspring, and in-laws, regardless of the amount of care giving, demonstrating the potential cascading effect of the illness through the family. Use of services displayed no direct association with spouse health and well-being, but service utilization interacted with illness severity. The relationship between severity of illness and spouse health was lower under conditions of high service utilization than under conditions of low service utilization.

[8] Martens, L., & J. Addington. "The psychological well-being of family members of individuals with schizophrenia." *Social Psychiatry and Psychiatric Epidemiology*, 2001, 36, 128-134.

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Measures

The S-QoL, based on Calman's approach to the subject's point of view, is a multidimensional instrument that is sensitive to change

Abstract

The authors developed a self-administered instrument to assess health-related quality of life (HRQL) among people with schizophrenia. The S-QoL, based on Calman's approach to the subject's point of view, is a multidimensional instrument that is sensitive to change. The scale is a 41-item questionnaire with eight subscales (psychological well-being, self-esteem, family relationships, relationships with friends, resilience, physical well-being, autonomy and sentimental life) and a total score. In-depth interviews with patients determined the pertinent issues for item development. The validation study, performed with 207 patients, showed high internal consistency reliability, reproducibility and responsiveness. Construct validity was confirmed using established clinical and HRQL measures. S-QoL covers domains that differ from areas tapped in other measures, with greater responsiveness. The S-QoL is an efficient instrument for the measurement of the impact of schizophrenia on individuals' lives.

[9] Noh, S., and R.J. Turner, R.J. "Living with psychiatric patients: Implications for the mental health of family members." *Social Science and Medicine*, 1987, 25, 263-271.

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Measures

'Objective' and 'subjective' family burden, and extent of psychological distress among family members

Abstract

Current treatment policy has resulted in large numbers of ex-hospitalized psychiatric patients residing with family members in the community. However, little is known about the emotional consequences for family members. This paper focuses on the relationship between level of chronic strain, as indexed by 'objective' and 'subjective' family burden, and extent of psychological distress among family members of ex-hospitalized psychiatric patients. This relationship is assessed within a multivariate model that also considers eventful experience as an additional source of stress and social support and mastery as potential stress mediators. The author found the variable of mastery, or sense of personal control, to be by far the most powerful predictor of distress among family members. When mastery was considered in regression analyses the modest correlations between 'objective' and 'subjective' family burden and distress scores disappeared. However, assessment of interactions indicated that strain is independently associated with distress among those subjects who scored relatively low on the mastery scale. Our most general conclusion is that the presence of some patients tends to be associated with substantial psychological costs for some families.

Other (2)

[1] El-Serag, HB. "Impact of Irritable Bowel Syndrome: Prevalence and Effect on Health-Related Quality of Life." *Rev Gastroenterol Disord*, 2003, 3 (suppl 2); S3-S11.

File

Not available

Measures

Chinese version of Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The study design was to explore and assess the health-related quality of life (HRQOL) of irritable bowel syndrome (IBS) patients in the population. Random clustered sampling involving permanent inhabitants aged 18 - 80 yr was carried out under stratification of urban and suburban areas in Guangdong Province. Altogether 231 IBS patients fulfilling the Rome II criteria and 636 Non-IBS as control were collected. The impact of IBS on HRQOL was evaluated using the Chinese version of SF-36.

(1) There were no statistically significant differences between IBS and Non-IBS groups in aspects of sex, age educational level, and distribution according to areas ($P > 0.05$). (2) IBS patients reported significantly poorer HRQOL than controls (Non-IBS) on all SF-36 subscales ($P < 0.05$). The patients had poorer HRQOL than the Non-patients, but their differences weren't significant ($P > 0.05$). (3) The scores on all SF-36 subscales were highly associated with the frequency of abdominal pain in IBS patients ($P < 0.05$); They were also correlated to degree of effects of IBS symptoms on life reported by IBS patients ($P < 0.05$); The association between the scores and the symptom of fatigue which is the most extra-intestinal symptom in IBS was significant ($P < 0.05$); (4) Copying style was highly correlated to the eight SF-36 subscales; IBS still had a significant impact on patients after partialing out the effect of copying style.

IBS symptoms had a negative impact on HRQOL and the SF-36 could be adopted to detect the differences between IBS group and Non-IBS group, which may be used as an outcome measure in future treatment studies. However, the development of IBS-specific measures of quality of life is necessary.

[2] El-Serag HB and NJ Talley. "Systematic Review: Health-Related Quality of Life in Functional Dyspepsia." *Aliment Pharmacol Ther*, 2003, 15, 18:387-93.

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QOLM Other El-Serag 2003.pdf

Measures

Measures of health-related QOL assess health perception as well as physical, emotional and social function, and this is referred to as functional status

Abstract

Quality of Life (QOL) in medicine has many meanings but is a subjective entity that broadly refers to those factors that make life worth living for the individual patient with a disease. Measures of health-related QOL assess health perception as well as physical, emotional and social function, and this is referred to as functional status. Such measurement is now considered to be a key factor in the assessment of patients with conditions such as functional dyspepsia, where there is chronic or recurrent unexplained pain or discomfort centered in the upper abdomen. QOL measures may be used to try and discriminate among a number of disease groups or to assess change in disease status over time; different approaches are usually necessary to meet these goals.

Veteran (11)

[1] Hume F and D Summerfield. "After the war in Nicaragua: a psychosocial study of war wounded ex-combatants." *Med War* 1994 Jan-Mar, 10(1):4-25.

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Measures

Quantitative (General Health Questionnaire [GHQ] and clinical interview) and qualitative (personal narrative)

Abstract

Despite 150 wars in the Third World since 1945, there have been virtually no psychosocial studies of war-wounded ex-combatants. This community study of 72 such men, on average 4.9 years post-injury, had both quantitative (General Health Questionnaire

[GHQ] and clinical interview) and qualitative (personal narrative) components. Most men were coping adaptively. However their overall GHQ scores were significantly higher than an ex-combatant control group, suggesting relative psychological vulnerability ($P = 0.001$). 13 (18 per cent) had post-traumatic stress disorder (PTSD) though in only three was this clinically significant, two of whom were aggressive alcoholics. Social dysfunction was a better indicator of the minority who needed psychological help than a diagnosis of PTSD.

The one in three with a severe physical disability were not at greater risk than the rest of the group. Personal narratives illuminated the ways subjects had registered and responded to their war experiences. Identification with the social ideals being defended by the war effort had been psychologically bolstering. Ten severely disabled ex-Contra guerrillas, who had fought on the other side, were also interviewed. The availability of appropriate training/work, and thus the economic fortunes of the whole society, are likely to be major determinants of long-term psychosocial outcomes. Six illustrative personal histories are appended.

[2]Black DW, .et al. "Quality of life and health-services utilization in a population-based sample of military personnel reporting multiple chemical sensitivities." *J Occup Environ Med.* 1999 Oct, 41(10):928-33.

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Not available

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The authors sought to assess quality of life and health-services utilization variables in persons with symptoms suggestive of multiple chemical sensitivity/idiopathic environmental intolerance (MCS/IEI) among military personnel. The authors conducted a cross-sectional telephone survey of a population-based sample of Persian Gulf War (PGW) veterans from Iowa and a comparison

group of PGW-era military personnel. A complex sample survey design was used, selecting subjects from four domains: PGW active duty, PGW National Guard/Reserve, non-PGW active duty, and non-PGW National Guard/Reserve. Each domain was sub-stratified by age, gender, race, rank, and military branch. The criteria for MCS/IEI were developed by expert consensus and from the medical literature.

In the total sample, 169 subjects (4.6 percent) of the 3695 who participated (76 percent of those eligible) met the criteria for MCS/IEI. Persons who met the criteria for MCS/IEI more often reported the following than did other subjects: more than 12 days in bed due to disability, Veteran's Affairs disability status, Veteran's Affairs disability compensation, medical disability, and unemployment. MCS/IEI cases also had higher outpatient rates of physician visits, emergency department visits, and inpatient hospital stays. Subjects who met the criteria for MCS/IEI more often reported impaired functioning on each Medical Outcomes Study 36-Item Short Form subscale, compared with those who did not meet the criteria. The authors concluded that although the diagnosis of MCS/IEI remains controversial, the persons who met our criteria for the disorder are functionally impaired.

[3] Weinberger, M., et al. "An evaluation of a brief health status measure in elderly Veterans. " *Journal of the American Geriatrics Society*, 1991, 39, 691-694.

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Measures

136-item Sickness Impact Profile

Abstract

The study design was to examine the feasibility of a brief 36-item health status measure in elderly male veterans, by comparing it with the 136-item Sickness Impact Profile Cross-sectional study in which

all subjects completed both measures in a random order. It was conducted at the Durham VAMC General Medicine and Geriatrics Clinics using a convenience sample of 25 male veterans aged 65 and older (mean age = 73.5 years; 68 percent white; 68 percent currently married; mean annual income = \$7,000). Two well-validated health status measures were used, the Sickness Impact Profile and the SF-36.

The SF-36 took less time to administer than the Sickness Impact Profile in both the Geriatrics Clinic (mean: 15 verses 33 minutes) and General Medicine Clinic (mean: 14 verses 21 minutes). Although SIP scores consistently displayed a more optimistic picture of respondents' health compared with the SF-36, the two instruments were highly correlated: overall functioning ($r = 0.73$), physical functioning ($r = 0.78$), and social functioning ($r = 0.67$).

These two measures provide a similar ranking of elderly male veterans' health status. The significantly shorter administration time of the SF-36 is an attractive feature for both researchers and clinicians interested in assessing health status.

[4] Weeks, W.B., et al. "Differences in health-related quality of life in rural and urban Veterans." *American Journal of Public Health*, 2004, 94 (10), 1762-1767.

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Measures

Health-related quality-of-life scores (physical and mental health component summaries)

Abstract

The authors sought to determine whether disparities in health-related quality of life exist between veterans who live in rural settings and their suburban or urban counterparts. The authors determined health-related quality-of-life scores (physical and mental health component summaries) for 767,109 veterans who had used Veterans Health Administration services within the past 3 years. The

authors used rural/urban commuting area codes to categorize veterans into rural, suburban, or urban residence.

Health-related quality-of-life scores were significantly lower for veterans who lived in rural settings than for those who lived in suburban or urban settings. Rural veterans had significantly more physical health comorbidities, but fewer mental health comorbidities, than their suburban and urban counterparts. Rural-urban disparities persisted in all survey subscales, across regional delivery networks, and after they controlled for socio-demographic factors.

When compared with their urban and suburban counterparts, veterans who live in a rural setting have worse health-related quality-of-life scores. Policymakers, within and outside the Veterans Health Administration, should anticipate greater health care demands from rural populations.

[5] McKenzie, D.P., et al. "Psychological health of Australian Veterans of the 1991 Gulf War: an assessment using the SF-12, GHQ-12 and PCL-S." *Psychological Medicine*, 2004, 34(8), 1419-1430.

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Measures

The 12-item Short Form Health Survey (SF-12), 12-item General Health Questionnaire (GHQ-12), Posttraumatic Stress Disorder Checklist--Specific (PCL-S) and Military Service Experience (MSE) questionnaire were administered

Abstract

Elevated rates of psychological morbidity and symptomatology have been widely reported in 1991 Gulf War veterans. The present study used brief self-report instruments to compare the psychological health of Australian Gulf War veterans with that of a randomly sampled military comparison group. The 12-item Short Form Health Survey (SF-12), 12-item General Health Questionnaire (GHQ-12), Posttraumatic Stress Disorder Checklist--Specific (PCL-S) and Military Service Experience (MSE) questionnaire were administered to

1424 male Australian Gulf War veterans and 1548 male Australian Defense Force members who were operational at the time of the Gulf War conflict, but were not deployed there.

The Gulf War veterans exhibited poorer psychological health, as measured by the above three instruments, than the comparison group members. For Gulf War veterans, the number of stressful experiences, as measured by the MSE questionnaire, was correlated with scores on the three instruments. SF-12 mental health component summary scores and PCL-S, but not GHQ-12, differed significantly between Gulf War veterans and comparison group members who had been on at least one active deployment.

More than a decade after the 1991 Gulf War, Australian Gulf War veterans are exhibiting higher levels of current (past month) psychological ill-health, as measured using the GHQ-12 and PCL-S, as well as lower mental health status, as measured by the SF-12, than the comparison group. Although not a replacement for formal psychiatric diagnosis, instruments such as those above may aid in the assessment of veterans' psychological health.

[6] Mroczek, D.K. and A. Spiro, A. "Change in life satisfaction during adulthood: Findings from the Veterans affairs normative aging study." *Journal of Personality and Social Psychology*, 2005, 88(1), 189-202.

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QOLM Veteran Mroczek 2005.pdf

Measures

Life satisfaction

Abstract

Change in life satisfaction was modeled over a 22-year period in 1,927 men. A curvilinear relationship emerged. Growth-curve models indicated that life satisfaction peaked at age 65 and then declined, but showed significant individual differences in rate of change. Extraversion predicted variability in change, with higher levels associated with a high and flat life satisfaction trajectory.

Time-varying physical health and marital status were associated with higher life satisfaction. Proximity to death was associated with a decline in life satisfaction. On measurement occasions that were within 1 year before death, trajectories showed steeper decline, and this effect was not attributable to declines in self-rated physical health. The findings are at odds with prior (cross-sectional) research showing that subjective well-being improves with aging.

[7] Schok, M.L. and J. de Vries. "Predicting overall quality of life and general health of Veterans with and without health problems," *Military Psychology*, 2005, 17(2), 89-100.

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Measures

World Health Organization Quality of Life Assessment Instrument-100 (WHOQOL-100)

Abstract

The purpose of this study was to describe quality of life (QOL) of Dutch New Guinea veterans with and without health problems and to identify predictors of overall QOL and general health using the World Health Organization Quality of Life Assessment Instrument-100 (WHOQOL-100). Current health problems in New Guinea veterans negatively affect overall QOL and general health; physical health; psychological health; level of independence; social relationships; and important features of the environment, when compared with their healthy counterparts. Predictors of overall QOL and general health differed between veterans with and without health problems, with the emphasis on quality of psychological health, social relationships, and level of independence as a means of improving the overall QOL and general health among veterans with health problems.

[8] Bookwala, J., et al. "The long-term effects of military service on quality of life: The Vietnam experience." *Journal of Applied Social Psychology*, 1994, 24(6), 529-545.

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Measures

Health-related behaviors, a series of life transitions experienced after the age of 40, and satisfaction with various components of life, as well as life as a whole

Abstract

In this study, the authors examined the effects of military service during the Vietnam War on the quality of life in middle adulthood for a cohort of men characterized by a privileged socioeconomic status. The final sample included 374 men who, upon graduating from an Ivy League college in 1966, performed military service in Vietnam, engaged in military service during this time in regions other than Vietnam, or did not serve in the military. As indices of quality of life in the middle years, the study team used a set of health-related behaviors, a series of life transitions experienced after the age of 40, and satisfaction with various components of life, as well as life as a whole.

Multivariate analyses of variance and chi-square analyses revealed significant differences among the sample subgroups on several quality-of-life indices. The subgroup of Vietnam veterans reported more frequent alcohol use than the non veterans. In terms of midlife transitions, the Vietnam veterans were most likely to have changed careers and to have moved residence, and the least likely to feel lonely in middle adulthood. Compared to the Vietnam veterans and the Vietnam-era veterans, the non-veteran group was least likely to have questioned their values, experienced depression, or to have moved to a new home.

Finally, the Vietnam veterans were significantly less satisfied with their careers, finances, and with life in general, compared to their non-veteran counterparts; however, they reported more satisfaction with their male friendships than did Vietnam-era veterans. These

findings suggest that the Vietnam War experience is associated with lower quality of life during middle adulthood in certain domains, even among a select group of individuals, of high socioeconomic status, whose privileged background could have presumably protected them from the adversities of the Vietnam War.

[9] Kazis LE, et al. "Health-Related Quality of Life in Patients Served by the Department of Veterans Affairs: Results from the Veterans Health Study." *Arch Intern Med*, 1998, 23, 158(6):626-32.

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QOLM Veteran Kazis 1998.pdf

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The study objective was to describe health status of veterans and examine relationships between variables. The sample consisted of: 1,667 patients from the Veterans Health Study, with the following characteristics: mean age=62 years, 92 percent white, 58 percent married, 52 percent annual income <= \$20,000, 58 percent <=12 years education. Patients received the SF-36, a health exam, clinical assessments, and medical history review. Collection occurred in three stages, each eight months apart. Veteran outpatients had significantly worse health than non-VA populations.

[10] Singh JA, et al. "Health-Related Quality of Life, Functional Impairment, and Healthcare Utilization by Veterans: Veterans' Quality of Life Study." *Journal of the American Geriatric Society*, 2005, 53(1):108-13.

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QOLM Veteran Singh 2005.pdf

Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The study design was to describe the health status of veterans receiving care in a veterans integrated service network (VISN). The authors used a cross-sectional survey with prospective follow-up. They conducted the study at former Upper Midwest VISN 13 (now a part of VISN 23), a regional Veterans Affairs (VA) network comprising five inpatient facilities and associated outpatient clinics. The surveyed all veterans in VISN 13 who had at least one inpatient or outpatient encounter between October 1, 1997, and March 31, 1998.

Health-related quality of life (HRQOL) assessed using subscales and component summaries from the 36-item short form for veterans (SF36-V), functional status assessed according to limitations in activities of daily living (ADLs), healthcare utilization assessed according to outpatient visits and hospitalizations, and death.

Of 70,334 eligible veterans, 40,508 responded and reported baseline HRQOL significantly lower than that of the general U.S. population for the physical (35.6, $P < .001$) and mental (46.4, $P < .001$) component summary scores (PCS and MCS, respectively) of the SF36-V. Many reported complete inability or some difficulty in completing ADLs such as getting in and out of a chair (35.1 percent) and walking (45.3 percent). More than 58 percent indicated some degree of difficulty with at least one of the ADLs. In multivariate analysis, PCS and MCS were significantly associated with subsequent use of inpatient and outpatient care and with mortality.

The low quality of life and associated high rates of health services utilization in VA patients imply a need for innovative strategies to improve the HRQOL and functional status of this population.

[11] Voelker MD, et al. "HealthRelated Quality of Life in Gulf War Era Military Personnel." *American Journal of Epidemiology*, 2002, 155(10):899-907.

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Measures

Medical Outcomes Study Short Form 36-items Health Survey (SF-36)

Abstract

The study objective was to compare the health-related quality of life (HRQOL) of military personnel deployed to the Gulf War versus those not deployed. The sample consisted of 3,695 personnel, most of whom were male, ≤ 25 years at time of Gulf War, married, enlisted, of the Army service branch, and white. A telephone survey was conducted five years post-conflict, including the SF-36. Non-deployed personnel reported better health. Deployed personnel had worse SF-36 scores across all domains. Independent risk factors for poorer HRQOL among deployed veterans included smoking, military preparedness, and pre-deployment health. After adjusting for these risk factors, deployed veterans still showed slightly poorer HRQOL.

