The PQOL (Perceived Quality of Life)

A Quality of Life Instrument

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User's Manual

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Purpose of this Manual

This document describes the development, scoring, and potential uses of the Perceived Quality of Life Scale (PQoL), a measure based on a model defining quality of life as evaluation of major categories of fundamental life needs. Scale items were developed using human needs theory (Maslow, 1943; Doyal and Gough, 1991) and interviews with different populations of older adults, well persons, and persons with disabilities to establish the content of the instrument. The measure is consistent with the needs based theory of quality of life (Hunt and McKenna, 1992) and the World Health Organization Definition of quality or life as people's "perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" [italics added] (Bonomi et al., 2000; WHOQoL Group, 1994).

Originally the PQoL was used in a briefer 12-item version for assessing the quality of life of persons following intensive care (Patrick et al., 1988). It was later expanded to 19 items to include areas of functional status considered important to persons with varying levels of wellness and disability. Since its original use, it has been more widely applied to a number of different patient and general population groups. (See application references at end of this document).

This measure also incorporates the areas of dysfunction included in the Sickness Impact Profile (SIP) developed in the United States (Bergner et al, 1981) and the Functional Limitations Profile (FLP), a culturally-adapted and UK weighted version of the SIP developed in the United Kingdom (Patrick and Peach, 1989). The PQoL can be correlated with SIP or FLP Category Scores to investigate the relationship between functional status and satisfaction with functioning (see Patrick et al, 2000 on development of the PQoL).

The PQoL is also part of a generic health and quality of life outcomes package being developed at the University of Washington that includes the assessment of functional status using the Short Profile of Illness Impact developed from the SIP, the PQoL, and a current health state desirability or preference measure. For more information on this package and its development, contact Donald Patrick

User Agreement

The University of Washington holds the copyright to all language versions of the PQOL.

Users of the PQOL are *not* authorized to make *any* changes to the instrument. Because the developers are interested in further reliability and validity documentation, PQOL users are kindly asked to address all inquiries concerning this manual and provide copies of any publications or reports resulting from its use to Dr. Donald Patrick:

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USER AGREEMENT

Conditions for use of the Perceived Quality of Life Instrument (PQOL)

Date:,
Day Month Year
CONTACT INFORMATION
Name:
Agency/University/Company:
Title:
Full Address:
Country:
Phone: Fax:
E-mail:
• Title: • Disease or disorder:
• Type of research
• Primary outcome measure or end point:
• Design:
• Number of expected respondents (total):
• Number of expected administrations of the questionnaires per respondent:
• Length of the follow-up (if any):
• Planned study date:
• Name of the funder:
• Other questionnaires used in the study:

• Number of countries/language versions involved:

SPECIFY:

Norwegian $\square 23$

USA (Spanish) \square 29,

USA (English) ⊠30,

IMPORTANT REMARK: THE PQOL MAY BE USED IN THE ABOVE MENTIONED INVESTIGATIONS WHEN THE FOLLOWING AGREEMENT IS COMPLETED AND SIGNED BY "USER".

« Person, University, Company» referred hereinafter as « User » wishes to use the **PQOL** in the above mentioned versions.

The UNIVERSITY OF WASHINGTON distributes the **PQOL** and its translations available in the following languages: U.S. English, U.S. Spanish, and Norwegian.

Therefore, User and UNIVERSITY OF WASHINGTON agree as follows:

1. UNIVERSITY OF WASHINGTON's obligations

UNIVERSITY OF WASHINGTON shall deliver the original **PQOL** and/or the translations requested by "User" subject to the following conditions:

- The translations requested are available, and
- The present agreement is duly completed and signed by "User"

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"User" shall not modify, abridge, condense, adapt, recast or transform the **PQOL** in any manner or form, including but not limited to any minor or significant change in wordings or organisation in **PQOL**, without the prior written agreement of UNIVERSITY OF WASHINGTON, which agreement shall not be unreasonably withheld or delayed.

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"User" shall not translate **PQOL**, without the prior written agreement of **the Authors**.

2.3 No reproduction

"User" shall not reproduce the **PQOL** except for the limited purpose of generating sufficient copies for use in investigations stated hereunder and shall in no event distribute copies of the **PQOL** to third parties by sale, rental, lease, lending, or any other profit-making means.

2.4. Publication

In case of publication of study results, "User" shall cite (1) "Patrick DL, Danis M, Southerland LI, and Hong G (1988) Quality of life following intensive care. <u>J Gen Int Med</u> 3(3):218-223." And (2) Patrick DL, Kinne S, Engelberg RA, Pearlman RA. (2000). Functional Status and Perceived Quality of Life in Adults with and without Chronic Conditions. <u>Journal of Clinical Epidemiology</u> 53: 779-785" in reference section of the publication. (New publications may be added and older ones deleted).

2.5 Provision of data

All data, results and reports obtained by, or prepared in connection with the **PQOL** shall remain the User's property. However, UNIVERSITY OF WASHINGTON may request the User to share data, results and reports obtained through the use of the **PQOL**, which request User can accept or reject in its sole and unfettered discretion. UNIVERSITY OF WASHINGTON shall ensure the anonymisation of such data at three levels, by the removal of: any patient identification, any university or company identification and any therapy name. UNIVERSITY OF WASHINGTON will classify and reorganize such anonymous data and therefore, shall hold all intellectual property rights regarding these data when and if submitted to the data pool.

UNIVERSITY OF WASHINGTON may provide such reorganized data to third parties, for analysis in education, research, consulting, and specifically for the

evaluation of cross-cultural equivalence and development of reference values for this **PQOL** or for any other similar project.

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2.6.1 Royalty fees (Authors)

The use of the **PQOL** is free of author's royalty fees.

2.6.2 Distribution fees (UNIVERSITY OF WASHINGTON)

The use of the **PQOL** in studies is subject to a distribution fee payable to UNIVERSITY OF WASHINGTON, of an amount of 100 dollars for general and administrative expenditures plus 50 dollars per language version requested. This fee includes provision of a user manual and scoring program

The use of the **PQOL** in non-funded academic research in developing countries or by students is subject to a \$25 fee for the instruments and user manual.

2.6.3 Invoicement

For the use of the **PQOL**, at the time of execution of this agreement, "User" shall pay an amount of 100 dollars for general and administrative expenditures plus 50 dollars per language version and "User" shall pay such invoice within thirty (30) days of the date of this agreement.

3. Copyright Infringement

The **PQOL** was developed by Donald L. Patrick, Ph.D. at The University of Washington. Donald L. Patrick holds copyright over the PQOL and all its present and future translations. Each new translation will be made available to third parties once it is available, through UNIVERSITY OF WASHINGTON, under the conditions described in the present document.

If, at any time during the term of this agreement, « User » learns of any infringement by a third party of any Intellectual Property Rights in connection with the **PQOL**, « User » shall promptly notify UNIVERSITY OF WASHINGTON. UNIVERSITY OF

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4. Confidentiality

All and any information related to the **PQOL** including but not limited to the following: information concerning clinical investigations, creations, systems, materials, software, data and know-how, translations, improvements ideas, specifications, documents, records, notebooks, drawings, and any repositories or representation of such information, whether oral or in writing or software stored, are herein referred to as confidential information. Likewise, any information provided by User to **Authors** relating to this Agreement, including information provided in this agreement, shall be treated as confidential information.

In consideration of the disclosure of any such confidential information to the other, each party agrees to hold such confidential information in confidence and not divulge it, in whole or in part, to any third party except for the purpose specified in this agreement.

5. Use of name

It is agreed that UNIVERSITY OF WASHINGTON shall not disclose, whether by the public press or otherwise, the name of "User' or institution", to any third party to this agreement except to the copyright holder(s) of the **PQOL**.

6. Liability

6.1 In case of breach of contract

In the event of total or partial breach by UNIVERSITY OF WASHINGTON of any of its obligations hereunder, UNIVERSITY OF WASHINGTON's liability shall be limited to the direct loss or damage (excluding loss of profit and operating losses) suffered by "User" as a result of such breach and shall not include any other damages and particular consequential damages.

6.2 In the scope of the use of the "Questionnaire"

Under no circumstances may **Authors** or UNIVERSITY OF WASHINGTON be held liable for direct or consequential damage resulting from the use of the **PQOL**.

6.3 In the event of non-renewal of this Agreement

In the event of non-renewal of this Agreement by UNIVERSITY OF WASHINGTON for any cause or failure by UNIVERSITY OF WASHINGTON to conclude a new agreement with "User" upon the expiry of this Agreement, UNIVERSITY OF WASHINGTON will have no liability for payment of any damages and/or indemnity to "User".

7. Term and termination

This agreement shall be effective as the date of its signature by "User" and shall continue for a term of 10 (ten) years at least or until the term of the study above mentioned in SUMMARY OF THE STUDY.

Either party may terminate this Agreement immediately upon providing written notice to the other party in the event of: (a) the other party's unexcused failure to fulfil any of its material obligations under this Agreement or (b) upon the insolvency or bankruptcy of, or the filing of a petition in bankruptcy or similar arrangement by the other party. User may terminate this Agreement for any reason upon 90 days written notice.

Upon expiration or termination of this Agreement UNIVERSITY OF WASHINGTON may retain in its possession confidential information it acquired from **PQOL** while under contract. The obligations which by their terms survive termination, include, without limitation, the applicable ownership, confidentiality and indemnification provisions of this Agreement, shall survive termination.

8. Assignment

This Agreement and any of the rights and obligations of "User" are personal to the "User" and cannot be assigned or transferred by "User" to any third party or by operation of law, except with the written consent of UNIVERSITY OF WASHINGTON notified to "User".

9. Separate Agreement

This Agreement holds for the above mentioned study only. The use of the **PQOL** in any additional study of the "User" will require a separate agreement without additional fees, unless significant updates have been added to the user manual (new edition, etc.).

10. Entire Agreement, Modification, Enforceability

The entire agreement hereto is contained herein and this Agreement cancels and supersedes all prior agreements, oral or written, between the parties hereto with the respect to the subject matter hereto.

This Agreement or any of its terms may not be changed or amended except by written document and the failure by either party hereto to enforce any or all of the provision(s) of this Agreement shall not be deemed a waiver or an amendment of the same and shall not prevent future enforcement thereof.

If any one or more of the provisions or clauses of this Agreement are adjudged by a court to be invalid or unenforceable, this shall in no way prejudice or affect the binding nature of this Agreement as a whole, or the validity or enforceability of each/and every other provision of this Agreement.

11. Governing law

This Agreement shall be governed by and construed in accordance with the laws of the State of Washington. Any disputes will be adjudicated first through the UNIVERSITY OF WASHINGTON and subsequently through courts in the State of Washington.

IN WITNESS WHEREOF, the parties hereto have caused this agreement to be executed by their duly authorised representatives as of the date first above written.

User/University/Company:	UNIVERSITY OF WASHINGTON
Name:	Name:
Title:	Title:
Signature:	Signature:
Date:	Date:

Introduction and Significance

Definition

This instrument is a 19-item measure of satisfaction with physical, psychological, and social functioning and universal needs that define quality of life (PQOL).

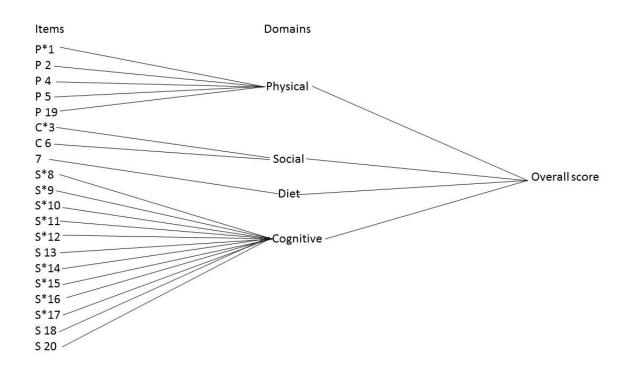
Description

The Perceived Quality of Life Scale (PQoL) is based on a theoretical model defining quality of life as evaluation of major categories of fundamental life needs. Scale items were developed using human needs theory (Maslow, 1943; Doyal and Gough, 1991) and interviews with different populations of older adults, well persons, and persons with disabilities to establish the content of the instrument. The measure is consistent with the needs based theory of quality of life (Hunt and McKenna, 1992) and the World Health Organization Definition of quality of life as people's "*perceptions of their position* in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" [italics added] (Bonomi et al., 2000; WHOQoL Group, 1994).

As stated previously, originally the PQoL was used in a briefer 12-item version for assessing the quality of life of persons following intensive care (Patrick et al., 1988). It was later expanded to 19 items plus a single global item to include the evaluation of satisfaction with areas of functional status considered important to persons with varying levels of wellness and disability. Since its original use, it has been more widely applied to a number of different patient and general population groups. (See application references at end of this document).

Conceptual

"How dissatisfied or satisfied are you with ..."



Methods Used for Testing the Psychometric Performance of the PQOL

Measurement Model

The response scale for the PQOL ranges from 0=extremely dissatisfied to 10=extremely satisfied. Factor analyses of the 19-item PQoL were conducted on data obtained from 2500 well older adults participating in a health promotion/disease prevention project conducted by the University of Washington and Group Health Cooperative of Puget Sound. These analyses, conducted using the "PROMAX" rotation in SAS, resulted in three factors labeled as follows:

P = Satisfaction with physical health and well-being

S = Satisfaction with social health and well-being

C = Satisfaction with cognitive health and well-being

Item 7 did not appear to fall into any factor and is best to use on its own. Subscale scores for satisfaction with physical, social, and cognitive health can be used in analyses as well as the overall score. Item-response analyses are currently being conducted to confirm these scores and domain structure.

Internal consistency

Internal consistency (Cronbach's alpha) for the original 12 item PQoL scale is 0.88 or above for both ill and well older adults. In a study of patients with chronic obstructive pulmonary disease, the internal consistency of the 19 item PQoL was examined in 90 respondents (Guttman-Cronbach alpha = 0.91; Patrick et al., 2001).

Using the three factor scores and item 17 in a higher-order factor analysis, an overall single factor emerged, leading to an overall PQOL score.

Test retest

In an unpublished analysis of the 2-week test-retest reliability of the PQoL on well adults, the overall score showed an ICC of 0.84.

Validity

Convergent and Discriminant (Known Groups)

In a sample of patients in intensive care, functional status correlated only moderately with perceived quality of life (r = 0.49, p < 0.01). Objective measures of patients' material and social resources did not predict satisfaction (Patrick et al., 1988). In an evaluation of the association between self-reported functional status and quality of life in adults with and without chronic conditions, the PQoL was lowest for persons using wheelchairs and highest for older well adults. Scores decreased as Sickness Impact Profile (SIP) scores increased. Overall, being older, reporting better functional status, and having fewer

depressive symptoms were significantly associated with higher quality of life (adjusted R(2) = 0.60). This pattern held for most subgroups, although the association was much lower for adults with AIDS and younger well adults where ceiling effects were observed in functional status. Functional status and perceived quality of life are highly associated but are distinct in many populations. Depressive symptoms and self-rated health are important mediators. This pattern of association supports the validity of the PQoL (Patrick et al., 2001).

Administration Guidelines

Instructions for Interviewers

This questionnaire asks about satisfaction with health and life in general. For each item, the respondent is to rate their level of satisfaction on a scale from 0 to 10 where 0 is *extremely dissatisfied* and 10 is *extremely satisfied*. Have the respondent look at the scale on a card (See CARD I below) and give you a number between 0 and 10. Record that number on the scale sheet.

NOTE: The exception in regards to scale, is item 20 that addresses "happiness" and is included for examination of convergent validity within the instrument. Here the respondent is to rate his/her happiness on a scale from 0 to 10 where 0 is *extremely unhappy* and 10 is *extremely happy* (See CARD 2 below). Total PQoL score should correlate highly with this single item.

Say to the Respondent

I want to talk to you now about your satisfaction with your health and other fundamental aspects of your life. Some people are more or less satisfied or dissatisfied with the different aspects of their lives. We want you to think about your own life situation and tell us just how satisfied or dissatisfied <u>you</u> are. I want you to give us a number on a scale of 0 to 10 where 0 is extremely dissatisfied and 10 is extremely satisfied. I want you to look at the scale and give me a number between 0 and 10 which best represents how satisfied or dissatisfied you fell.

SHOW RESPONDENT CARD 1 FOR ITEMS 1-19 AND CARD 2 FOR ITEM 20.

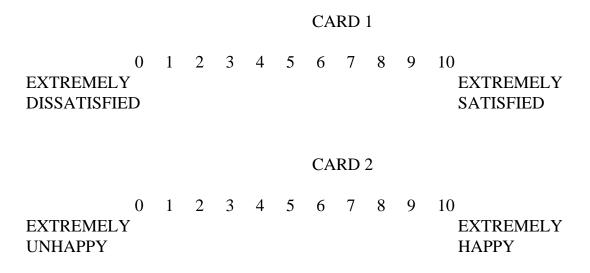
If the Respondent has Difficulty with Direct Assignment of Number from 0-10

Some respondents unfamiliar with rating scales or with questionnaires in general may have difficulty in directly assigning a number from 0 to 10 to indicate their level of satisfaction/dissatisfaction. For these respondents, a two or three step procedure can be followed.

Verbal anchors on a card (satisfaction/dissatisfaction for items 1-19 and happy/unhappy for item 20) can be shown to these respondents as follows:

Extremely dissatisfied/unhappy	= 0
Somewhat dissatisfied/unhappy	= 1 or 2
A little dissatisfied/unhappy	= 3 or 4
Neither satisfied/happy or dissatisfied/unhappy	= 5
A little satisfied/happy	= 6 or 7
Somewhat satisfied/happy	= 8 or 9
Extremely satisfied/happy	= 10

Ask the respondent to give you the word that best indicates his or her level of satisfaction/happiness. For verbal categories that have two numerical scores, then ask the respondent to choose the lower number or higher number that indicates their perceived level of satisfaction/happiness. Most respondents are able to choose between the two numbers. In cases where respondents cannot or refuse to choose one of the two numbers, then toss a coin to decide (heads=lower number, tails=higher number).



Use

In general, no recall period has been used with the PQoL as satisfaction "at the moment of instrument administration" is what is being requested. If all other instruments in the questionnaire have specific recall periods, it is wise to give a recall period to the PQoL as well. A recall period of "in the last week" or "in the last month" can be used. The PQoL, in usage with the SIP, should contain "think of yourself today" which was the original intent of the SIP.

INSTRUCTIONS FOR PREPARING SELF-ADMINISTERED VERSION

In preparing your questionnaire for self-administration, please **NOTE** that the anchors of *Extremely dissatisfied* and *Extremely satisfied* should be **COMPLETELY OUTSIDE** the numbers **0** and **10** to indicate they are cognitive anchors outside the numbers. If they are put below the numbers, there may be a tendency of respondents to avoid using the extreme numbers.

For each question, please circle the number that indicates how dissatisfied or satisfied you are with that aspect of your life. A response of 5 means that you are neither dissatisfied nor satisfied.



P*1 How *dissatisfied* or *satisfied* are you with your physical health (the health of your body)?

(*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY

DISSATISFIED SATISFIED

P 2 How *dissatisfied* or *satisfied* are you with how well you care for yourself, for example, preparing meals, bathing, or shopping? (*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY DISSATISFIED

SATISFIED

C *3 How *dissatisfied* or *satisfied* are you with how well you think and remember? (*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY DISSATISFIED

SATISFIED

P 4 How *dissatisfied* or *satisfied* are you with the amount of walking you do? (*Please circle the number*)

3 5 1 2 8 10 **EXTREMELY EXTREMELY SATISFIED** DISSATISFIED P 5 How dissatisfied or satisfied are you with how often you get outside the house, for example, going into town, using public transportation, or driving? (Please circle the *number*) 0 1 3 5 10 **EXTREMELY EXTREMELY** DISSATISFIED **SATISFIED** How dissatisfied or satisfied are you with how well you carry on a conversation, for example, speaking clearly, hearing others, or being understood? (Please circle *the number)* 0 1 2 3 5 7 8 10 **EXTREMELY EXTREMELY** DISSATISFIED **SATISFIED** THE FOLLOWING ITEM IS ADMINISTERED WITH THE PQoL BUT DOES NOT FIT INTO A PARTICULAR DOMAIN How dissatisfied or satisfied are you with the kind and amount of food you eat? (*Please circle the number*) 0 1 3 5 6 8 10 **EXTREMELY EXTREMELY SATISFIED DISSATISFIED** S *8 How dissatisfied or satisfied are you with how often you see or talk to your family and Friends? (*Please circle the number*)

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EXTREMELY EXTREMELY

1

0

2

3

5

7

8

10

DISSATISFIED SATISFIED

S *9 How *dissatisfied* or *satisfied* are you with the help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands? (*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY

DISSATISFIED SATISFIED

S *10 How *dissatisfied* or *satisfied* are you with the help you give to your family and friends?

(*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY DISSATISFIED

SATISFIED

S *11 How *dissatisfied* or *satisfied* are you with your contribution to your community, for example, a neighborhood, religious, political or other group? (*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY

DISSATISFIED SATISFIED

S *12 How *dissatisfied* or *satisfied* are you with your work situation, for example, your current job, retirement for any reason, or never having worked?

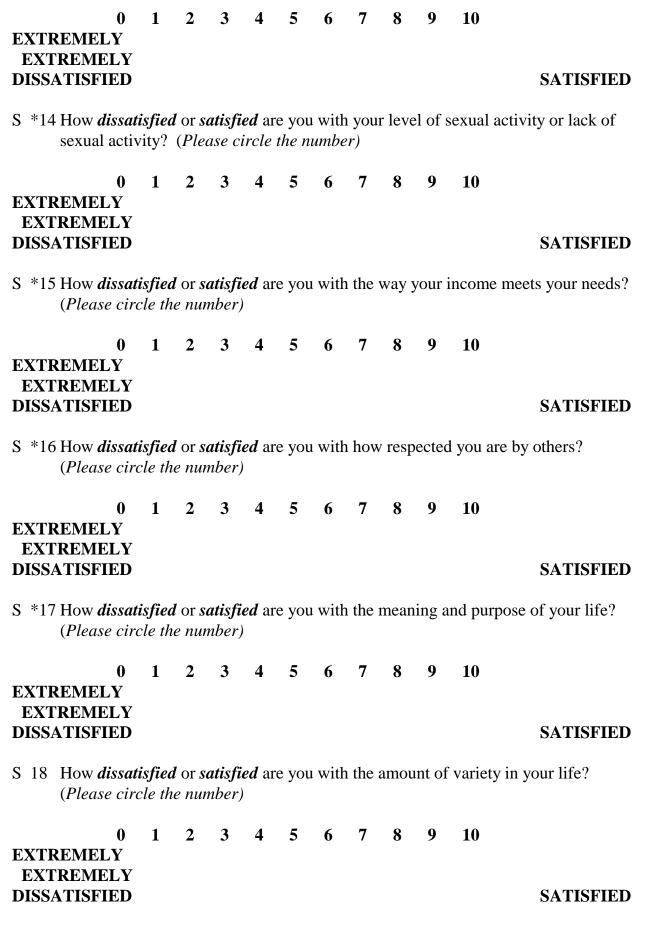
(*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY DISSATISFIED

SATISFIED

S 13 How *dissatisfied* or *satisfied* are you with the kind and amount of recreation or leisure you have? (*Please circle the number*)



P 19 How *dissatisfied* or *satisfied* are you with the amount and kind of sleep you get? (*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY DISSATISFIED

SATISFIED

THE FOLLOWING ITEM IS ADMINISTERED WITH THE PQoL AND CAN BE USED FOR CONVERGENT VALIDITY IN COMPARISON WITH THE OVERALL PQoL SCORE

S *20 How happy are you? (*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY EXTREMELY UNHAPPY

HAPPY

^{*}Indicates items from original 12-item version

Discussion

The main advantage of the PQoL is the ability to use this instrument and examine the relationship between function and satisfaction with function. It is easy to administer, was developed using a theoretical model and interviews with different populations. The measure has been used most widely in populations with chronic conditions. The main potential limitation is the use of a 0-10 scale. Some respondents unfamiliar with rating scales or with questionnaires in general may have difficulty in directly assigning a number from 0 to 10 to indicate their level of satisfaction/ dissatisfaction. For these respondents follow the explanations of cards 1 and 2 as explained above.

This measure also incorporates the areas of dysfunction included in the SIP developed in the United States (Bergner et al., 1981) and the Functional Limitations Profile (FLP), a culturally-adapted and UK weighted version of the SIP developed in the United Kingdom (Patrick and Peach, 1989). The PQoL can be correlated with SIP or FLP Category Scores to investigate the relationship between functional status and satisfaction with functioning (see Patrick et al., 2000 on development of the PQoL).

Scoring the PQOL

Scoring Instructions and Scale Characteristics

Nineteen item scores, 3 domain scores, a single item score for item 7 (satisfaction with diet) and an overall score based on the mean or median of the 19 item scores can be constructed. Internal consistency (Cronbach's Alpha) for the original 12 item PQoL scale is 0.88 or above for both ill and well older adults. In a study of patients with chronic obstructive pulmonary disease, the internal consistency of the 19 item PQoL was examined in 90 respondents. (Guttman-Cronbach alpha = 0.91), with a range of corrected item-total correlations from 0.33 on the sleep item to 0.71 on the work/current retirement item. Most respondents, including older adults express a moderate to high level of satisfaction. A population mean\median of 7.5 has been observed (N=3359). Interpretation of the measure in cross-sectional use is Dissatisfied is a score <7.5 and Satisfied is a score >7.5.

References

General References

Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. Med Care. 1981 Aug;19(8):787-805.

Bonomi, A. E., Patrick, D. L., Bushnell, D. M., Martin, M. (2000). Validation of the United States' version of the World Health Organization Quality of Life (WHOQOL) instrument. <u>Journal of Clinical Epidemiology</u>, 53, 19-23

Haave E, Hyland ME & Engvik H.: Physical and emotional aspects of self-reported health status. A two-factor model of the short-form Breathing Problems Questionnaire. Chronic Respiratory disease. February 2005, vol. 2, no. 1, pp. 21-26(6).

Haave E, Hyland ME & Skumlien S.: The relation between measures of health status and quality of life in COPD. Chronic Respiratory disease (in press).

Haave E, Skumlien S & Engvik H.: Norsk versjon av "The Perceived Quality of Life Scale" (PQoL), brukt på pasienter med alvorlig kronisk obstruktiv lungesykdom (KOLS) og friske voksne personer. Tidsskrift for Norsk Psykologforening (in press). (In english: Norwegian version of the PQoL, tested for COPD patients and healthy adults. Journal of the Norwegian Psychological Association)

Hornquist JO. The concept of quality of life. Scand J Soc Med. 1982;10(2):57-61.

Maslow HA A theory of human motivation. Psychol Rev 1943; 50, 370-96

Doyal L, Goug I. A theory of human need. New York: Guilford Press, 1991.

Hunt SM, McKenna SP. The QLDS: a scale for the measurement of quality of life in depression. Health Policy. 1992 Oct;22(3):307-19.

Patrick DL, Peach H. Disablement in the community. Oxford: Oxford University Press, 1989. The Functional Limitations Profile is available from the author.

World Health Organization Quality of Life Group. The development of the World Health Organization Quality of Life Assessment Instrument (WHOQOL). In J. Orley & W. Kuyken (Eds.), Quality of life assessment: International perspectives (pp. 41-57). Berlin: Springer-Verlag, 1994.

<u>Publications on the PQoL and its Development:</u>

Patrick DL, Danis M, Southerland LI, and Hong G (1988) Quality of life following intensive care.

J Gen Int Med 3(3):218-223.

Norburn J, Patrick DL, Beresford SA, and Stein J (1987) Functional status and perceived quality of life among older persons. <u>Proceedings of the 21st Public Health Conference on Records and Statistics</u> 13-15 July 1987. Washington DC: National Center for Health Statistics.

Submitted or In Preparation:

Patrick DL, Engelberg R, Kinne S. Refinement and responsiveness of the Perceived Quality of Life Scale (PQOL). In preparation.

Known published uses of the PQoL:

- Baxter J, Shetterly SM, Eby C, Mason L, Cortese CF, Hamman RF. (1998) Social Network factors Associated with Perceived Quality of Life. <u>Journal of Aging and Health</u>. 10 (3): 287-310.
- Caldwell EM, Baxter J, Mitchell CM, Shetterly SM, Hamman RF. (1998) The Association of Non-Insulin-Dependent Diabetes Mellitus with Perceived Quality of Life in a Biethnic Population: The San Luis Valley Diabetes Study. <u>American Journal of Public Health</u>. 88 (8): 1225-1229.
- Conn VS, Taylor SG, Casey B. (1992) Cardiac rehabilitation program participation and outcomes after myocardial infarction. Rehabilitation Nursing. 17 (2): 58-62.
- Hurel D, Loirat P, Saulnier F, Nicolas F, Brivet F. (1997) Quality of life 6 months after intensive care: results of a prospective multicenter study using a generic health status scale and a satisfaction scale. <u>Intensive Care Medicine</u>. 23: 331-337.
- Patrick DL, Beresford SA, Ehreth J, Diehr P, Picciano J, Durham M, Hecht J, Grembowski D (1995) Interpreting excess mortality in a prevention trial for older adults." <u>International Journal of Epidemiology</u> 24(Suppl 1): S27-S33.
- Patrick DL, Kinne S, Engelberg RA, Pearlman RA. (2000). Functional Status and PerceivedQuality of Life in Adults with and without Chronic Conditions. <u>Journal of Clinical Epidemiology</u> 53: 779-785

Patrick DL, Ramsey SD, Spencer AC, Kinne S, Belza B, Topolski TD. Economic evaluation of aquatic exercise for persons with osteoarthritis. Med Care. 2001 May;39(5):413-24.

- Patrick DL, Kinne S, Engelberg RA, Pearlman RA. Functional status and perceived quality of life in adults with and without chronic conditions. J Clin Epidemiol. 2000 Aug;53(8):779-85.
- Sawdon V, Woods I, Proctor M. (1995) Post-intensive care interviews: implications for future practice. <u>Intensive and Critical Care Nursing</u>. 11 (6): 329-332.
- Steiner RP, Looney SW, Hall LR, Wright KM. (1995) Quality of life and functional status among homeless men attending a day shelter in Louisville, Kentucky. <u>Kentucky</u> Medical Association Journal. 93: 189-195.
- Unutzer J, Patrick DL, Simon G, Grembowski D, Walker E, Rutter C, Katon W (1997)
 Depressive Symptoms and the Use of Health Services in HMO Patients Age 65 and
 Over: A Four-Year Prospective Study. <u>Journal of American Medical Association</u>.
 277 (20):1618-1623.

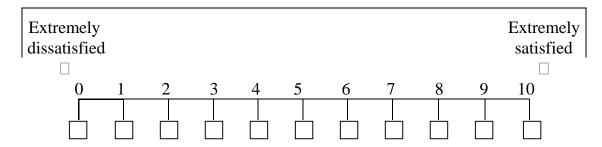
APPENDIX-A

INSTRUMENT

We would like to know how satisfied you are with different aspects of your life. Each item below has a scale where "0" is Extremely Dissatisfied and "10" is Extremely Satisfied. [For each item, mark an 🗷 in the box of the number that shows your own level of satisfaction.]

How dissatisfied or satisfied are you with:

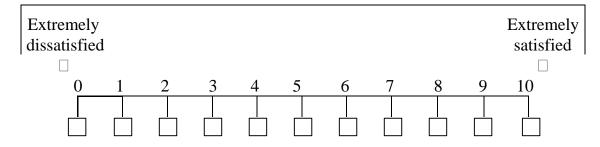
1 Your physical health (the health of your body)?



2 How well you care for yourself, for example, preparing meals, bathing, or shopping?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10

3 How well you think and remember?



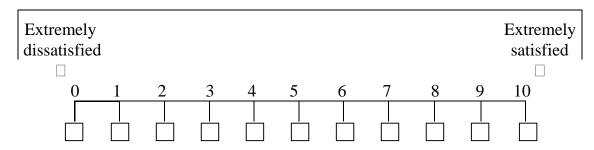
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How dissatisfied or satisfied are you with:

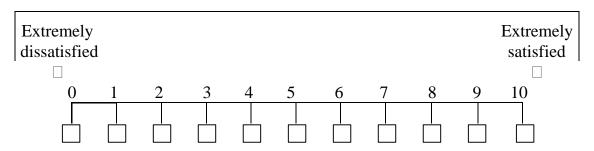
4 The amount of walking you do?

Extremely										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10

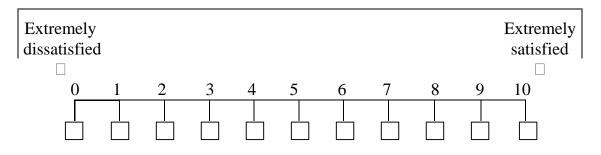
5 How often you get outside the house, for example, going into town, using public transportation or driving?



6 How well you carry on a conversation, for example, speaking clearly, hearing others, or being understood?



7 The kind and amount of food you eat?



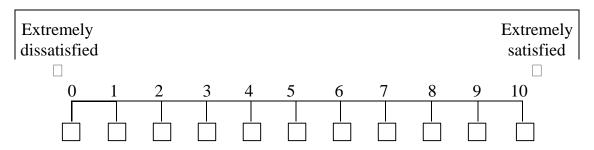
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How dissatisfied or satisfied are you with:

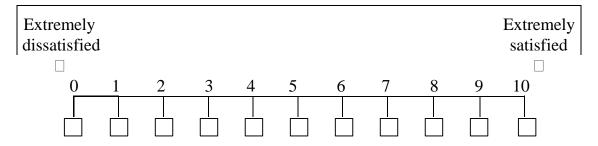
8 How often you see or talk to your family and friends?

Extremely dissatisfied	ı									Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10

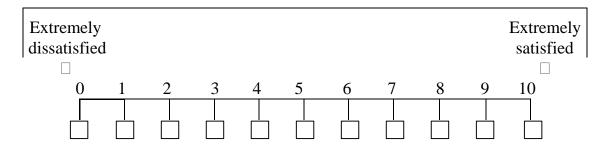
9 The help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands?



10The help you give to your family and friends?



11Your contribution to your community, for example, a neighborhood, religious, political or other group?



(Please turn the page)

31

How dissatisfied or satisfied are you with:

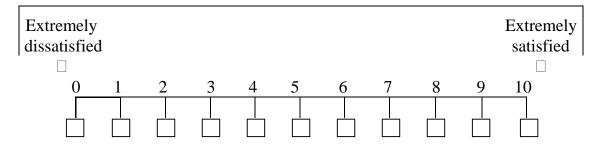
12Your retirement or current job?

Extremely	l									Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10

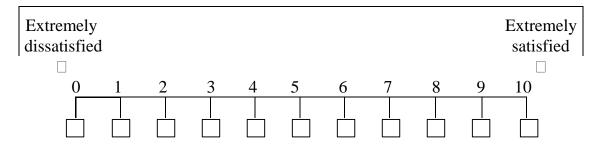
13The kind and amount of recreation or leisure you have?

Extremely dissatisfied	l									Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10

14Your level of sexual activity or lack of sexual activity?



15The way your income meets your needs?

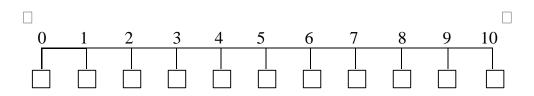


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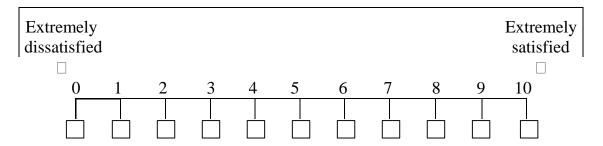
How dissatisfied or satisfied are you with:

16How respected you are by others?

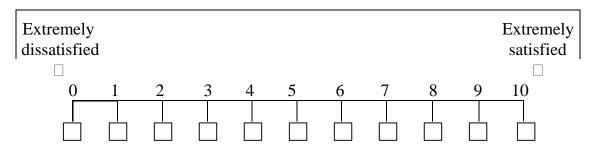
Extremely dissatisfied



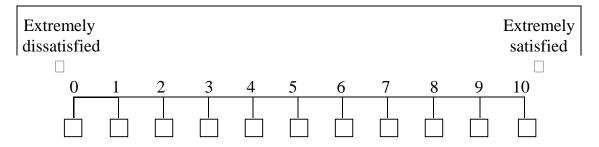
17The meaning and purpose of your life?



18The amount of variety in your life?



19The amount and kind of sleep you get?



(Please turn the page)

20How happy are you?

