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The Self-Perception and Relationships Tool (S-PRT): A novel approach to the measurement of subjective health-related quality of life

Mark J Atkinson*^{†1,2}, Paul M Wishart^{†3,4}, Bushra I Wasil⁵ and John W Robinson^{6,7}

Address: ¹Department of Psychiatry, University of Calgary, Calgary, Alberta, Canada, ²Pfizer Inc, San Diego, California, USA, ³Department of Surgery, University of Calgary, Calgary, Alberta, Canada, ⁴Spirituality Research Institute (Sri) Inc., Calgary, Alberta, Canada, ⁵Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada, ⁶Department of Oncology and Program in Clinical Psychology, University of Calgary, Alberta, Canada and ⁷Tom Baker Cancer Centre, Calgary, Alberta, Canada

Email: Mark J Atkinson* - mark.j.atkinson@pfizer.com; Paul M Wishart - pmwishart@SpiritualityResearchInstitute.com; Bushra I Wasil - biwasil@ucalgary.ca; John W Robinson - johnrobi@cancerboard.ab.ca

* Corresponding author †Equal contributors

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Abstract

Background: The Self-Perception and Relationships Tool (S-PRT) is intended to be a clinically responsive and holistic assessment of patients' experience of illness and subjective Health Related Quality of Life (HRQL).

Methods: A diversity of patients were involved in two phases of this study. Patient samples included individuals involved with renal, cardiology, psychiatric, cancer, chronic pelvic pain, and sleep services. In Phase I, five patient focus groups generated 128 perceptual rating scales. These scales described important characteristics of illness-related experience within six life domains (i.e., Physical, Mental-Emotional, Interpersonal Receptiveness, Interpersonal Contribution, Transpersonal Receptiveness and Transpersonal Orientation). Item reduction was accomplished using Importance Q-sort and Importance Checklist methodologies with 150 patients across the participating services. In Phase II, a refined item pool (88 items) was administered along with measures of health status (SF-36) and spiritual beliefs (Spiritual Involvements and Beliefs Scale – SIBS) to 160 patients, of these 136 patients returned complete response sets.

Results: Factor analysis of S-PRT results produced a surprisingly clean five-factor solution (Eigen values > 2.0 explaining 73.5% of the pooled variance). Items with weaker or split loadings were removed leaving 36 items to form the final S-PRT rating scales; Intrapersonal Well-being (physical, mental & emotional items), Interpersonal Receptivity, Interpersonal Contribution, Transpersonal Receptivity and Transpersonal Orientation (Eigen values > 5.4 explaining 83.5% of the pooled variance). The internal consistency (Cronbach's Alpha) of these scales was very high (0.82–0.97). Good convergent correlations (0.40 to 0.67) were observed between the S-PRT scales and the Mental Health scales of the SF-36. Correlations between the S-PRT Intrapersonal Well-being scale and three of SF-36 Physical Health scales were moderate (0.30 to 0.46). The criterion-related validity of the S-PRT spiritual scales was supported by moderate convergence (0.40–0.49) with three SIBS scales.

Conclusion: Evidence supports the validity of the S-PRT as a generally applicable measure of perceived health status and HRQL. The test-retest reliability was found to be adequate for most scales, and there is some preliminary evidence that the S-PRT is responsive to patient-reported changes in determinants of their HRQL. Clinical uses and directions for future research are discussed.

Background

Conceptual framework

With the emergence of collaborative and participatory models of health service delivery patient reported outcomes (PRO) have become an increasingly important criteria of service effectiveness [1-3]. It is not uncommon to find subjective health related quality of life (HRQL) measures along side more traditional clinical indicators of health outcomes. Nevertheless, subjective measures of disease and treatment impact are still viewed with some skepticism [4]. In part, such concern is due to the weaker and sometimes ambiguous causal associations between subjective PRO's and more objective clinical change [5-7]. To address ambiguous association with health status, there is a tendency for health outcome researchers to opt for disease specific instrumentation with a heavy focus on the assessment of clinical symptoms, functional status, and general health states [7].

Subjective HRQL is thought to characterize the interaction between the circumstance or experiences associated with illness and patients' personal values and expectations [8]. It is argued that the weaker association between HRQL measures and clinical conditions are acceptable because subjective measures are more responsive to, and congruent with, aspects of patients' evaluation, perception, interpretation, and processes of adaptive coping with illness [9]. While more objective PRO measures may be more predictably responsive to changes in the physiological and psychiatric targets of treatment, patients' subjective perception of well-being is associated with good treatment outcomes – directly or indirectly impacting such things as treatment compliance, program follow-through, and satisfaction with care, and in some circumstances duration of survival [10-15].

The conceptual and methodological underpinnings for the Self-Perception and Relationship Tool (S-PRT) arose out of an attempt to reconcile two apparently incompatible positions regarding the assessment of individuals' experience of illness, the normative or quantitative approach and the ideographic or qualitative approach. While these approaches can be viewed as complementary [16,17], they are infrequently combined in a manner that is both useful to clinical investigators and feasible for routine support of clinicians' relationships with patients and their support networks.

Normative measurement is advantageous since its' measurement constructs are rooted in generalized conceptual and empirical frameworks. Individuals' scores on such measures can be interpreted by comparison with those of established reference groups and understood in the context of testable theoretical models and hypotheses. Typically, such measures are based on a reduction of unique

detail at the level of the individual respondent and emphasize what is relevant to all individuals. Normative methods tend to classify persons, while treating unique variation of individuals, rather unflatteringly, as unexplained error. This results in concise and feasible instrumentation, but often occurs at the expense of well-elaborated description of personal meaning. Consequently, clinicians often find it difficult to use such results to facilitate deep and unique interpersonal understanding with their patients.

On the other hand, advocates of qualitative approaches rightly emphasize the necessity of gaining clinical understanding at the level of the individual patient. Grounded and phenomenological approaches are typically used to explore and elaborate on the richness of individuals' perspectives, experiences, and goals (cf., [18,19]). Providers of patient-centered care instinctively favor this perspective since both view interpersonal understanding as the cornerstone of the caregiver-patient relationship. While qualitative approaches are expansive and rich, they are usually too unwieldy to be routinely applied to support clinical practice. Moreover, results from qualitative studies cannot easily be used to describe group differences, such as when assessing standards of practice or evaluating the effectiveness of service delivery. Within both practice and educational settings, advocates of the two approaches have attempted to integrate these two very valid, but quite different, approaches to patient assessment [16,20-22].

Early formulations: characteristics of a measure

Our initial discussion about development of a new HRQL instrument focused on the need to support patient care and health service delivery by providing clinicians with detailed information about the impact of illness on patients' well-being [23]. It was recognized that the psychometric validity of such an instrument would depend on its ability to describe normative group similarities and differences, but that the real value would be determined by its ability to help to strengthen clinician-patient relationships and facilitate three central objectives of good patient care: 1) To foster meaningful patient-centered dialogue and supportive therapeutic relationships [24]; 2) To identify patients with special needs for adjunctive support; and 3) To characterize patients' experience of the illness-health progression as well as the experiential impact of interventions over time.

Also at issue was the need to assure the general relevance of the measured dimensions across a wide range of patient groups. In this regard it was necessary to break rank with typical approaches to designing disease- and symptom-specific HRQL instrumentation, since they are based on the premise that measures depend on a careful specification of disease-specific contexts and experiences. This

method of gaining measurement precision was not seen as feasible across disparate and heterogeneous patient populations. Contributing to this challenge was our desire to cover the most common domains thought relevant to the study of HRQL [25]; encompassing physical, mental-emotional, social and, the less often considered spiritual experiences related to illness. After much discussion, it was decided that our approach to measurement design could not be specifically tied to a structured set of circumstances, events, or exemplars that would impose observational restrictions; and the 'constructs' associated with patient well-being could not be operationalized in a typical manner.

In order to achieve the normative psychometric performance that we required, measurement dimensions would have to be common across individuals, but would not rely on *what* was important to specific patient groups but rather *how* 'it' was important across patient groups, leaving the definition of life events and circumstances up to the patient – the specifics of which could later be explored with the patient in an interview setting. The question remained, whether common dimensions of patient well-being could be found across patients and what psychometric characteristics such dimensions would possess.

Conceptual foundations

The fundamental importance of respondents' definition of what is (subjectively) relevant to their well-being has led to a variety of non-traditional approaches to the quantitative measurement of HRQL and PROs in general. Without exception, these methods allow respondents to individually identify and rate what is most important to them. Another common feature is the use of various computational and classification techniques that provide a means to produce group statistics for comparative and summative purposes. Two better known HRQL examples are the Schedule for the Evaluation of Individual Quality of Life (SEIQOL) and the Patient Generated Index (PGI), both of which allow respondents to identify personally relevant groups of related activities/goals and rate them according to their subjective importance as determinants of life quality [26-29]. These measures and approaches have demonstrated that it is possible to design respondent-defined HRQL instrumentation that possesses adequate psychometric properties. These psychometric characteristics hinge on the consistency with which individuals evaluate and value aspects of the life experiences they choose to rate.

Several psychological disciplines address the consistency with which individuals create meaning around dimensions of personal experience. Personal Construct Theory (PCT) describes stable aspects of individuals' cognitive representations by identifying core dimensions of per-

sonal meaning. Empirically, PCT assessment of such meaning structures is based on comparative ratings on bipolar continua of perceived opposites. Important or 'deep' personal constructs are thought to comprise individuals' core belief systems, and define the dominant interpretive framework(s) that individuals apply when interpreting life events. To us, the basic principles of PCT seemed quite congruent with the purpose of the current instrumentation project, as stated by Kelly, "how the human process flows, how it strives in new directions as well as in old, and how it may dare for the first time to reach into the depths of newly perceived dimensions." [30]. Among qualitative health care researchers, the idea to use PCT is not a new one; for example, PCT based approaches have been used in the study of personal meanings associated with death and dying [31].

Scholars of cognitive constructivism, who suggest individuals' progressively elaborate personally relevant meaning through daily interaction with the world, provide another perspective on the creation of personal meaning. An important postulate is that personal relevance or meaning can be assessed by the degree to which emotional experience is generated when the belief system is activated or challenged [32]. Thus emotional states are viewed as inextricably tied to core perceptions of ourselves and our world [33]. Put more simply, if you know how an individual feels about an event, you are on the right path to discover what is most important to them and how they view and understand the emotionally relevant aspects of life situations. Not surprisingly, emotional ratings are often among the strongest covariates of HRQL; typically equal to, or stronger than, objectively defined (normative) indicators [34,35].

Many theoretical perspectives on human psychology suggest that our experiences and behavior is founded on a fundamental emotional distinction between pleasurable and aversive events. Although there is a growing body of research that suggests that this hedonic polarity is not truly a functional opposite in terms of cognitive information processing [36], there is longstanding acceptance of the centrality of hedonic balance as a determinate of mental health and subjective well-being [36-41]. Thus, a confluence emerged suggesting that the evaluation of core subjective meaning might be best described on a polar emotionally valenced continuum. Moreover, the intuitive appeal of a valenced emotional heuristic, to both patients and clinicians, could provide inherent face and clinical validity to the measure, as well as facilitate its use to further the interpersonal processes of clinical care.

It was through this process of learning, reasoning and debate that we began to examine a central idea that emotional perception might serve as a basis for the

measurement of subjective HRQL; one that might retain its relevance across a wide diversity of patient groups and illness-related experiences.

Methods

Scaling issues

The semantic differential method (SDM) (cf., [42,43]) seemed to be an obvious choice as a scaling paradigm for a several reasons. First, the methodology is well established as a reliable and generally applicable way to measure individuals' attitudes, preferences and perceptions that result from various real-life experiences [44-46]. For example: within health care, SDM has been used successfully to describe the experiences of patients and caregivers coping with chronic illness, as well as less tangible perceptions such as 'hope' in palliative care settings [47-49]. Of added benefit, there is convincing evidence that the semantic differential measurement approach is very responsive to changes occurring as a result of psychotherapy [43,50], educational, medical, and pastoral training [51-53], and interactions between patients/clients and their caregivers [54]. Other research using semantic differential methods has also demonstrated its usefulness as a screening tool (c.f., [27,55]).

Originally, the SDM was used to explore the connotative meaning of words by asking respondents to rate their understanding of a particular word or idea on a scalar continuum between two opposite or polar adjectives. Such ratings provide a sense of the ways in which respondents understand the meaning of the reference material(s).

In the current study, we chose to substitute attitudinal and sensory scale anchors for pairs of emotionally opposite perceptions of illness-related experiences. It was hoped that these perceptual rating scales would allow respondents to provide meaningful ratings of the impact of personally relevant illness-related experiences. However, unlike earlier applications of SDM, we would leave choice of the specific life events to being rated was left almost completely open to respondents. A fundamental design principle was to characterize the most important emotional perceptions that patients have about the impact of illness on experience that they identified as important across various domains of life.

Item generation and evaluation

Perceptual rating scales for the future instrument were developed through the work of five sequential, and similarly tasked Patient Focus Groups. The work of each focus group was improved upon by the next. Members of these groups included patients (n = 31) and interested clinicians (n = 6) receiving or providing inpatient or outpatient treatment for one of the following conditions: Cancer (n = 12), chronic renal failure (n = 3), psychiatric

illness (n = 10), and acute life-threatening cardiac events (n = 6). Participants typically possessed a high degree of interest in, and awareness of, the personal and social impact of illness on their lives.

In order to orient focus group members to the tasks at hand, a package was provided several days before the date a particular group was to be convened. The package included a statement of study purpose, a description of key measurement objectives of the instrument, definitions of the six areas (or life domains) to be assessed by the new instrument, namely; patients' perceptions of their physical well-being, mental-emotional well-being, social connectedness, contribution to others' well-being, feelings of spiritual connectedness, and orientation towards spiritual growth processes. The package also included a list of illness impact statements (to which they could add), and the most recent version of the scales proposed by the previous focus group.

Dr. Robinson, a clinical psychologist and co-author with previous experience leading focus groups, facilitated the groups. Participants were led to view themselves as experts on their experience through a facilitative stance of curiosity and incomplete understanding [56]. The task put to each member of the group was to think about their own experiences of illness ("illness events") and the emotional impact of these events on the six areas/domains of their lives. The groups worked on identifying positive and negative emotional terms that describe these experiences ("emotional descriptors").

The following stems were used to orient participants to each of the six domains:

Physical Well-being: Within my illness experience, I physically feel I am:

Mental Emotional Well-being: Within my illness experience, I feel I am:

Interpersonal Receptiveness: My relationships help me feel I am:

Interpersonal Contribution: Towards those who are emotionally close to me, I feel I am:

Spiritual Receptiveness: Universal beliefs & principles or a divine presence help me feel I am:

Spiritual Orientation: Towards universal beliefs & principles or a divine presence I feel I am:

An example was provided to illustrate the process of developing rating scales (items) within the focus group sessions:

Domain of Life Experience: Interpersonal Contribution

Illness-event: Increased Dependency on Others

Potential Descriptors of Patient Experience: Helpless, Embarrassed, etc.

Opposite Poles: Capable, Confident, etc.

Over the course of the focus group session, participants proposed and discussed new scale anchors as well as the meaning of opposite emotional terms. From this information, a drafts of bi-polar perceptual rating scales were sequentially refined, new scales were added, confusing or unbalanced terms were reworded, and redundancies between items were removed or clarified. The five focus groups generated and refined 128 differential scales across six domains of life experience. Frequency response options provided continua on which respondents could rate their emotional perceptions of relevant illness events across six life domains.

In order to help assure at least a grade six reading level, the pre-pilot version of the 128-item pool was given to two sixth grade language arts teachers for review. Ten patients were also asked to complete the item pool and comment on the completion time, the understandability of instructions, and the clarity of both the task and item layout. Feedback was used to evaluate wording and design of items, as well as respondent burden.

Item reduction

Patients across seven participating service areas (i.e., renal, cancer, cardiology, mental health, chronic pain, diabetes, and alternative medicine) took part in an item Q-sort that was designed to reduce the item pool to contain items that were important to a majority of respondents. Twenty to twenty-five patients from each service area ($n = 150$) took part in this phase of the study. In some service areas where implementation of the Q-sort method was difficult or impractical (e.g., in waiting rooms with short waits), an Item Importance Checklist was employed. For each of the six HRQL domains, participants either sorted item cards or rated the relative importance of each item based on their illness experiences. A comparison of the distributions of Q-sort and Item Importance Checklist data reveal no difference between the two methods, although the Q-sort allowed for more meaningful interaction between participants and research assistants.

Items were selected for the reduced item pool if they met one of the two criteria – the item was endorsed or sorted as "very important" by at least 45% of the patients across all service areas or endorsed by at least 70% of the patients in any one area. Due to a more heterogeneous endorsement rating of items in the spirituality/transpersonal domain, items that were endorsed by 65% of patients in any two areas were also included (For the sake of brevity, these data have been omitted but are available upon request). The reduced item pool consisted of 88 items covering the six domains of life experience.

Main psychometric study

For the purpose of psychometric evaluation, the reduced 88 S-PRT item pool was administered along with measures of physical and mental health related quality of life (SF-36 v2) and spiritual beliefs (Revised Spiritual Involvements and Beliefs Scale – SIBS-R). Supplemental questions were also added to gather basic demographic and clinical information. Finally, individuals were asked to rate themselves with regards to their degree of spirituality/religiosity, self-esteem, social relationships, existential worry, difficulties coping with illness, and acceptance of illness. These questions were designed for the study in consultation with a psychologist on the project and took the form of self-statements (e.g., "I am a religious person" or "My illness has caused me to worry about life and death issues.").

Study instruments

MOS SF-36 version 2

Together, the SF-36 version 1 and version 2 are the most widely used generic measures of self-perceived health status and HRQL in health care [57-59]. Both versions of the SF-36 consist of 36 items that assess eight dimensions of health status: 1) Physical Functioning, 2) Physical Role Limitations due to physical health problems, 3) Bodily Pain, 4) General Health, 5) Vitality (energy/fatigue), 6) Social Functioning, 7) Emotional Role Limitations due to emotional problems, and 8) Mental Health that characterize respondents' current state of psychological distress/well-being [60,61]. This instrument has been extensively tested and validated across a wide range of illness conditions and patient populations [60,62] and shown to be responsive to changing clinical conditions over time [62,63].

The Spiritual Involvement and Beliefs Scale (SIBS)

The SIBS is a relatively new instrument developed by Hatch and colleagues [64] and subsequently revised (R. B. Hatch, personal communication, July 6, 2001). It is designed to assess both spiritual and religious practices and beliefs across a wide variety of religious/spiritual traditions. The SIBS is self-administered and contains 26 Likert-type items measuring four dimensions: External/

Ritual, Internal/Fluid, Existential/Meditative, and Humility/Personal Application. The instrument has been tested in various patient populations, including those using general family practice care. It has been shown to have good test-retest reliability ($r = 0.92$), internal consistency (Cronbach's $\alpha = 0.92$) and validity when compared to other established instruments (e.g., Spiritual Well Being Scale). The SIBS was chosen because it avoids the cultural-religious biases inherent in many measures of its type and it operationalizes spirituality more broadly than other measures of religiosity.

Self-Perception and Relationships Tool

The test item pool consists of 88 items that measure patients' perceptions of the emotional impact of illness on the physical, mental-emotional, social and spiritual dimensions of illness experience. Six experiential domains of life experience are assessed using on semantic differential rating scales, namely: Physical Well-being, Mental-Emotional Well-being, Interpersonal Receptiveness, Interpersonal Contribution, Transpersonal Receptiveness, and Transpersonal Orientation. The Interpersonal Receptiveness domain assesses respondents' perceptions of what significant relationships contribute to their own sense of social well-being. Rating scales in the Interpersonal Contribution domain describe respondents' perceptions of what they contribute to the well-being of those around them. A similar distinction is made in the spiritual/transpersonal domain, with Transpersonal

Receptiveness assessing respondents' perceptions of how they benefit from beliefs or faith in a higher power, and Transpersonal Orientation is thought to assess core attitudes associated with spiritual practice.

Recruitment procedures and sample characteristics

One hundred and thirty eight patients from six service areas (i.e. cardiology, renal, mental health, cancer, chronic pain, and sleep disorders) participated in the final phase of the validation study (participation rate 86% = 138/160). A brief description of these services is provided in Table 1.

In most cases, patients that were deemed medically stable and well enough, were approached by a practitioner or a service area research coordinator who asked if they would like to participate in a research project investigating the psychosocial and spiritual impact of illness on patients' lives. If patients expressed an interest, a pamphlet describing the study was provided. The participation rate varied widely, between 30% on the inpatient cardiology unit to 95% in the outpatient renal dialysis clinic. These patients were contacted by a research assistant who provided additional information on the study and addressed any questions they had about the project. If still interested, participants were given a package containing the questionnaires, a study consent form, and a detailed description of the project. Complete confidentiality of results was assured.

Table 1: A description of participating services

Patient Population	Sex Ratio (m:f)	Service Description	Sample Size	Proportion Female*	Age (sd)**	Duration of Illness In Years***
Cardiology	2:1	Inpatients receiving medical management and diagnostic procedures admitted for cardiac and postoperative thoracic surgery	30	40.0%	66.2 (12.7)	6.6 (11.9)
Renal Dialysis	3:2	Outpatients receiving regular hemodialysis	29	58.6%	61.4 (15.2)	10.5 (8.8)
Mental Health	2:3	Inpatient psychiatric services and outpatient attendees in a day program providing various forms of individual and group medical and psychosocial therapies	19	57.9%	43.5 (8.8)	8.2 (8.5)
Cancer	0:1	Outpatients attending a genitourinary follow-up clinic, being seen for counseling, or attending meditation or support groups	29	44.8%	59.1 (14.1)	2.4 (4.0)
Chronic Pain	1:8	Outpatients attending medical and psychosocial treatments for chronic pain of difference etiologies	14	92.9%	47.1 (11.4)	8.4 (7.4)
Sleep Disorders	1:6	Outpatients receiving assessment and/or treatment for breathing problems during sleep	15	40.0%	50.0 (11.6)	5.4 (7.2)

* Chi-square(5) = 13.3, $p < .05$ ** F(1,5) = 10.55, $p < .0001$ ***F(1,5) = 2.69, $p < .05$

When obtaining patient consent, participants were also asked if they would consider taking part in a follow-up post-test. Forty patients agreed to participate in this follow-up activity. These individuals were mailed the S-PRT four to six weeks later, along with a set of questions asking how much they thought their physical, mental-emotional, social and spiritual experiences had changed since the last time they completed the S-PRT. Twenty-eight individuals returned the post-test, a response rate of 70%.

Results

Study participants were very diverse with respect to the types of illness, illness severity, degree of functional impairment, and length of time that they had been coping with their illness condition. Table 1 presents the sample sizes, the gender composition, age, and reported duration of illness of participants in each service area. Significant differences between services were found on each of these variables.

The majority of participants (49.3%) indicated they were Protestant, 15.9% indicated they were Catholic, 2.9% were Lutheran, 1.4% were Jewish, 1.4% were Hindu. The following religions were mentioned by one respondent each, Pagan, Mormon and Baha'i. No differences were observed across service areas by participants' stated religious affiliation.

S-PRT factor structure

A Principal Components Analysis factor analysis with varimax rotation was used to empirically identify the constructs measured by the S-PRT items (Table 2). An orthogonal rotation was used due to the conceptual distinctiveness of the physical, mental/emotional, social and spiritual dimensions of patients' illness experiences. An initial solution (Eigen values > 1.00) resulted in nine factors, but the last three factors contained only a few weakly loaded items. A solution of 5 factors (Eigen values > 2.0) was the cleanest, with over 2/3 of items having loadings greater than .70. This solution converged in 6 iterations and explained 73.5% of the total pooled variance (available from authors on request). The assignment of items to these five factors was remarkably consistent with the original six assessment domains, particularly given the relatively small ($n = 136$) and heterogeneous patient sample.

Items with weaker or split loadings across factors were removed and a final factor solution explained a total of 83.5% of the pooled variance. Factor 1 contained three items from the original Physical Well-being domain and five items from the Mental-Emotional domain. Together the Intrapersonal Well-being factor explained 18.8% of the pooled variance. Factor 2 was composed of seven items assessing their receptiveness to spiritual experience. The Transpersonal Receptivity factor explained 16.7% of

the total variance. Factor 3 was made up of seven items assessing respondents' perceptions of their contribution to the well-being of others. The Interpersonal Contribution factor explained 16.5% of the variance. Factor 4 was comprised of seven items assessing the domain of interpersonal receptivity (16.2% of the variance). The final Factor 5 contained seven items assessing respondents' perceptions of their orientation towards a higher power or being. Transpersonal Orientation explained 15.3% of the variance.

The unweighted mean of items in each factor provided a scale score that ranged between +3 and -3. The basic psychometric and distributional properties of the final S-PRT scales are presented in Table 3 and the final instrument can be obtained at <http://www.s-prt.com/sprt.htm>.

Examination of the inter-correlations between the final scales (Table 4) confirmed what has been shown earlier regarding the close inter-relationships between the subjective perceptual dimensions of well being across all domains of life [65].

Test/re-test reliability and responsiveness estimates

Test – retest reliability coefficients were computed using data on 28 respondents to the follow-up administration of the S-PRT at 4–6 weeks. Lower than desirable test-retest reliability coefficients were observed on the Intrapersonal Well-being and Interpersonal Receptivity scales ($r^2 = .68$ and $.50$ respectively). Adequate stability reliabilities were observed for the Interpersonal Contribution, Transpersonal Receptivity and Transpersonal Orientation scales ($r^2 = .77, .81$ and $.89$). Higher stability coefficients in these domains may be due to the relative stability of intrinsically oriented belief systems over time and across circumstance. Due to the relatively small sample size employed in the factor analytic procedure and possible inflation of internal consistency estimates, the Cronbach's Alpha coefficients are also reported on the test retest sub-sample.

Criterion-related validity coefficients

The validity of the S-PRT was examined using three measures: Two established measures, one assessing physical and mental health-related quality of life (SF-36 v.2) and one measuring constructs associated with spiritual beliefs (i.e., Spiritual Involvement and Beliefs Scale). A third measure consisted of a series of ten self-statements, respondents were asked to rate the statements in terms of how similar each was to their beliefs and experiences with illness, social relationships, religious/spiritual beliefs, and self-esteem.

Criterion 1 – Health and Mental Health Status

The magnitude of observed correlations across many of the SF-36 scales was quite remarkable, given the diverse

Table 2: Rotated Final S-PRT Factor Matrix (PCA w/ Normalized Varimax rotation)

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
sprt1_2: Relaxed – Tense	0.765904	0.126488	0.174227	0.210059	0.170847
sprt1_7: Comfortable – Uncomfortable	0.810188	0.112724	0.177177	0.149595	0.194676
sprt1_11: At Ease – In Agony	0.806023	0.156198	0.209830	0.207579	0.199407
sprt2_4: Composed – Distraught	0.776262	0.159793	0.237609	0.213601	0.194655
sprt2_6: Optimistic – Discouraged	0.757015	0.272019	0.252487	0.206305	0.224987
sprt2_8: Confident – Unsure	0.794255	0.220842	0.252751	0.257178	0.140459
sprt2_9: Capable – Helpless	0.773045	0.239206	0.240902	0.255906	0.090500
sprt2_11: Certain – Uncertain	0.755713	0.263730	0.142988	0.260479	0.163744
sprt3_1: Valued – Worthless	0.306442	0.288372	0.256965	0.724346	0.317142
sprt3_2: Comforted – Distressed	0.339176	0.190541	0.229059	0.780652	0.289085
sprt3_3: Close – Distant	0.365069	0.147027	0.255139	0.781274	0.210217
sprt3_4: Connected – Isolated	0.372666	0.289838	0.246560	0.767451	0.214528
sprt3_5: Included – Excluded	0.319439	0.369555	0.300866	0.701795	0.224947
sprt3_6: Supported – Blamed	0.212290	0.217951	0.215613	0.844374	0.159439
sprt3_7: Accepted – Criticized	0.187775	0.207666	0.282948	0.807109	0.250181
sprt4_6: Forgiving – Resentful	0.234064	0.277061	0.767847	0.174509	0.283519
sprt4_7: Welcoming – Unreceptive	0.267249	0.235703	0.797278	0.221030	0.233982
sprt4_8: Accepting – Rejecting	0.175307	0.282161	0.801813	0.246268	0.261754
sprt4_9: Encouraging – Discouraging	0.267265	0.240680	0.713481	0.331334	0.185379
sprt4_10: Trusting – Distrusting	0.235102	0.214541	0.786012	0.168813	0.175872
sprt4_12: Understanding – Misunderstanding	0.317488	0.167972	0.756294	0.250444	0.162536
sprt4_15: Respectful – Disrespectful	0.201758	0.093795	0.774560	0.216227	0.231676
sprt5_5: Inspired – Uninspired	0.232477	0.767128	0.192724	0.259621	0.343534
sprt5_6: Comforted – Troubled	0.329334	0.650754	0.316778	0.250093	0.345596
sprt5_8: Accepted – Judged	0.260441	0.748832	0.342498	0.168430	0.275759
sprt5_9: Guided – Aimless	0.194918	0.809686	0.183812	0.191776	0.341644
sprt5_11: Embraced – Rejected	0.154139	0.762916	0.240371	0.305133	0.300942
sprt5_12: In Harmony – Out of Step	0.295655	0.751552	0.280743	0.211639	0.292652
sprt5_15: Sustained – Adrift	0.266614	0.788653	0.164279	0.247734	0.308835
sprt6_6: Listening – Ignoring	0.223518	0.334612	0.199378	0.227847	0.733169
sprt6_7: Receptive – Closed	0.246350	0.287743	0.298374	0.251853	0.761000
sprt6_8: Thankful – Demanding	0.290120	0.351701	0.276236	0.342784	0.662583
sprt6_9: Accepting – Critical	0.236834	0.277307	0.287704	0.235070	0.775268
sprt6_11: Approaching – Receding	0.251658	0.332675	0.246590	0.190326	0.761285
sprt6_12: Willing – Resisting	0.193367	0.408216	0.289721	0.237814	0.716361
sprt6_13: Connecting – Separating	0.173351	0.449445	0.249674	0.284322	0.729898
Expl. Var	6.788767	6.005182	5.943846	5.831431	5.496101
Prp. Totl	0.188577	0.166811	0.165107	0.161984	0.152669

Extraction Method: Principal Components Analysis. Rotation Method: Varimax with Kaiser Normalization. Rotation converged in 6 iterations.

Table 3: S-PRT Scale Characteristics

S-PRT Scales	# Items	Mean (Standard Deviation)	Skew	Cronbach's Alpha	Cronbach's Alpha (retest sample n = 28)
Intrapersonal Well-being	8	0.48 (1.5)	0.02	.82	.94
Interpersonal Receptivity	7	1.32 (1.5)	-0.75	.97	.97
Interpersonal Contribution	7	1.71 (1.2)	-1.04	.96	.96
Transpersonal Receptivity	7	1.12 (1.3)	-0.29	.96	.97
Transpersonal Orientation	7	1.24 (1.3)	-.042	.97	.97

Table 4: Pearson Intercorrelation Matrix (n = 136)**

	Intra-personal (Well-being)	Inter-personal (Receptivity)	Inter-personal (Contribution)	Trans-personal (Receptivity)
Interpersonal Receptivity	.66			
Interpersonal Contribution	.58	.64		
Transpersonal Receptivity	.59	.65	.63	
Transpersonal Orientation	.59	.68	.65	.79

** All correlations are significant at the .001 level (2-tailed).

patient samples and the generic nature of both the SF-36 and S-PRT rating scales (Table 5). As would be expected, given the common emotional roots of mental well-being, the highest correlations were observed between S-PRT ratings and the SF-36 scales associated with respondents' emotional states (i.e., Emotional Role Function and particularly the Mental Health scale). This observation provides initial evidence that- the S-PRT instrument assesses the psychological impact of patients' life experiences in terms of their distress/well-being.

In order to evaluate whether correlations between the S-PRT and the SF-36 Mental Health or Emotional Role Function scales might have been due to the strong influence of depression in the mental health and chronic pain samples, these correlations were rerun with these samples removed. These results (not reported here) revealed an increase in the association between the S-PRT Physical-Mental/Emotional subscales and the four SF-36 physical health scales. However, removal of primarily depressed or highly distressed patient samples did not greatly reduce the strength of association of S-PRT scales with the SF-36 Mental Health scale, suggesting that the measure is not solely responsive to the more extreme emotional perceptions of persons with mental illness.

Evidence of criterion related validity of the S-PRT Interpersonal scale can be seen in moderate correlations found with three of the Physical Health scales of the SF-36 (i.e., Physical Role, Pain, and perceptions of General Health). The absence of significant correlations between the S-PRT scales and the Physical Function scale of the SF-36 may reflect the fact that the S-PRT assesses the subjective emotional impact of physical conditions, not the physical condition itself.

Criterion 2 – Spiritual Involvement and Beliefs

Correlations between the Transpersonal S-PRT scales and the SIBS were moderate (Table 6). A weaker association was found between scores on the Existential-Meditative scale of the SIBS and both Interpersonal scales.

The areas of strongest association occurred with the SIBS Internal-Fluid and Existential-Meditative scales. This may reflect a shared emphasis on internal perceive and balanced emotional states by meditative and reflective respondents.

Patients' Endorsement of Self-statements: Participants' rated the degree to which they thought they were similar or dissimilar to each of 10 self-statements using a four point rating scale (i.e., Very much, Somewhat, Not much, and Not at all). These results provide some preliminary insight into the physical, psychological, social and religious context of the S-PRT ratings (Table 7).

Across all domains assessed by the S-PRT, patients' perceptions of self-esteem, supportive relationships and acceptance of their illness were positively associated with well-being. In contrast, stressed relationships, difficulties coping with illness, and preoccupation with existential issues were negatively associated with all scales of the S-PRT. The Intrapersonal Well-being scale was also negatively correlated with recent reductions in physical function and increased dependence on the assistance of others. Intriguingly, the Transpersonal Receptiveness scale of the S-PRT is differentially correlated with patients' ratings of their own spirituality versus religiosity (items 1 & 2 in Table 7), and may distinguish such individuals.

Significant differences were found on four of the five S-PRT scales between service area subsamples (see Table 8). The sources of observed group differences were primarily a result of fairly high S-PRT well-being scores reported by those in Cardiology compared to those in Mental Health and Chronic Pain. In general, we suggest that adaptive well-being scores range between +1 and +2, on a -3 to +3 scale.

Discussion

The results presented here build on a history of unique yet psychometrically sound HRQL instrumentation, which do not rely heavily on specific situational or disease-specific content. The S-PRT employs generally worded domain stems on which respondents' provide emotional-

Table 5: Pearson correlations between the SF-36 and the S-PRT Scales

S-PRT Scales	Physical Scales of the SF-36				Mental Scales of the SF-36			
	Physical	Physical Role Function	Pain	General Health	Vitality	Social Function	Emotional Role Function	Mental Health
Intrapersonal Well-being	-0.04	0.30***	0.30***	0.46***	0.49***	0.55***	0.51***	0.67***
Interpersonal Receptivity	-0.11	0.21*	0.21*	0.30***	0.30***	0.35***	0.44***	0.51***
Interpersonal Contribution	-0.08	0.19*	0.24**	0.22*	0.26**	0.31***	0.41***	0.44***
Transpersonal Receptivity	-0.09	0.23*	0.23*	0.23*	0.30***	0.36***	0.38***	0.45***
Transpersonal Orientation	-0.10	0.17	0.20*	0.18	0.15	0.32***	0.35***	0.40***

* Correlation is significant at the .05 level (2-tailed). ** Correlation is significant at the .01 level (2-tailed). *** Correlation is significant at the .001 level (2-tailed)

Table 6: Convergent validity coefficients between the spirituality scales of the S-PRT and the Spiritual Involvement and Beliefs Scale

S-PRT Scales	Spiritual Involvement and Beliefs Scale			
	External-Ritual	Internal-Fluid	Existential-Meditative	Humility-Personal Application
Intrapersonal Well-being	-0.01	0.06	0.10	-0.03
Interpersonal Receptivity	0.07	0.16	0.23*	-0.01
Interpersonal Contribution	0.11	0.19	0.28**	0.20*
Transpersonal Receptivity	0.40***	0.48***	0.48***	0.25**
Transpersonal Orientation	0.43***	0.49***	0.47***	0.30**

* Correlation is significant at the .05 level (2-tailed). ** Correlation is significant at the .01 level (2-tailed). *** Correlation is significant at the .001 level (2-tailed)

perceptual ratings of illness-related experiences that they identify as belonging to each domain. In this way, the instrument does not introduce the contextual restrictions often imposed by many disease-specific measures of HRQL. Such content specificity often results in gains of instrument performance at the expense of unique personal relevance and generalized relevance across patient groups [66]. The S-PRT allows individuals to provide ratings that are based on their own perceptions of the impact of illness on five experiential domains of HRQL. This provides the S-PRT with good face validity since the meaning of its domain stems and rating scales arise from the respondent's interpretation and experience. In addition, the emotional basis of the rating scales serves to strengthen the internal consistency of the scales and personal salience of individuals' responses.

An unexpected, but exciting observation was the distinct distribution of S-PRT items on factors as the original

hypothetical domains defined them; the only exception was that the Physical and Mental/Emotional domains merged completely. The clean factorial structure is most likely due to the combined effects of the clear distinctions made by respondents between their experiences within each domain and cognitive coherence associated with emotional ratings. As a result, there is a high degree of item covariation within each domain across respondents, despite the fact that each respondent uniquely defined and rated a unique set of situational experiences.

The current methodology may allow researchers to disentangle the interactions between objective situational determinants of HRQL and patients' subjective response to situational events, such interactions have presented a persistent challenge to developers and users of HRQL instrumentation [29,56]. By allowing respondents to select and rate personally relevant experiences on a common set of emotional rating scales may elucidate the sub-

Table 7: Pearson correlations between patients' evaluation of their current life experiences and the S-PRT scales

	Intrapersonal Well-being	Interpersonal Receptivity	Interpersonal Contribution	Transpersonal Receptivity	Transpersonal Orientation
I am Religious	.08	.18*	.13	.34***	.31***
I am Spiritual	-.05	.11	.02	.15	.30***
I have high Self-esteem	.53***	.44***	.45***	.47***	.45***
I have supportive relationships	.19*	.45***	.33***	.27**	.25**
My relationships are stressed	-.43***	-.40***	-.40***	-.25**	-.34***
My ADL are reduced	-.22**	-.06	-.05	-.10	-.06
My dependence on others has increased	-.20*	-.01	-.04	-.03	-.01
I have difficulties coping w/ illness	-.60***	-.24**	-.28***	-.34***	-.24**
I worry about life and death issues	-.41***	-.19*	-.26**	-.30***	-.22*
I have come to accept my illness	.44***	.29***	.38***	.46***	.36***

* Correlation is significant at the 0.05 level (2-tailed). ** Correlation is significant at the 0.01 level (2-tailed). ***Correlation is significant at the 0.001 level (2-tailed).

Table 8: ANOVA Comparisons of S-PRT Scale Scores by Service Area

Therapeutic Area	Intrapersonal Well-being	Interpersonal Receptivity	Interpersonal Contribution	Transpersonal Receptivity	Transpersonal Orientation
Renal (n = 28)	0.68 (1.4)	1.31 (1.6)	1.74 (1.1)	1.16 (1.3)	1.32 (1.3)
Cardiology (n = 29)	1.20 (1.4)	1.74 (1.4)	1.95 (1.2)	1.48 (1.1)	1.67 (1.1)
Mental Health (n = 19)	-0.42 (1.5)	0.49 (1.8)	1.16 (1.7)	0.53 (1.4)	0.77 (1.4)
Cancer (n = 28)	0.65 (1.4)	1.84 (1.2)	2.05 (0.9)	1.58 (1.1)	1.65 (1.2)
Chronic Pain (n = 14)	-0.67 (1.4)	1.14 (1.4)	1.28 (1.2)	0.75 (1.4)	0.78 (1.2)
Sleep Clinic (n-16)	0.56 (1.1)	0.84 (1.4)	1.61 (1.4)	0.80 (1.4)	0.80 (1.3)
All Groups (n = 134)	0.47 (1.2)	1.32 (1.5)	1.70 (1.2)	1.12 (1.3)	1.24 (1.3)
F value	5.41	2.78	1.74	2.34	2.30
p Value	.0001	.02	.12 (ns)	.045	.049

jective emotional/evaluative components of HRQL while retaining the personal relevance of the situations being rated.

The normative characteristics of the S-PRT allowed for statistical identification of significant group differences between patient samples. These differences occurred where one might expect them, with the lowest scores on four S-PRT scales found among respondents with chronic pain, depression/psychosis. The highest sense of well-being among patients was reported by the more acute cardiac conditions. The S-PRT also possessed another important characteristics of a normative HRQL instrument, namely a fairly convincing convergence with standard HRQL scales (i.e., SF-36 and SIBS). These normative characteristics suggest the instrument is suitable for use in

research applications employing traditional quantitative methodologies, such as examination of group differences between patient groups or treatment conditions.

To some, the absence of specific detail regarding specific circumstances of patients' lives may seem to limit the usefulness of S-PRT results; and results reveal few clues as to the specific reasons for variation in respondents' well-being ratings. Indeed, in the current study supplemental questions were required for the purpose of analysis in order to gain a fuller contextual understanding of the S-PRT ratings. Nevertheless, a central objective for development of the S-PRT was to foster patient-centered dialogue, and indeed the need for contextual clarification of patients' responses fits well with its intended purpose. Another appealing characteristic is that the S-PRT permits

assessment and screening of emotionally distressing issues without resorting to use of potentially restrictive or embarrassing questions about illness-specific events. Too many patients perceive such 'testing' as cold and uninviting; to the more vulnerable or private patient, such questions may be (defensively) viewed as invasive or offensive. Using the S-PRT, patients can be allowed to express illness-related distress in different areas of their lives without fears of over disclosure of personal events, yet 'leaving the door open' to define and explore potential issues within a consensually negotiated relationship with their caregiver.

Contributing to its validity as a qualitative interview tool, the S-PRT was developed through a well-grounded process in which patients developed a rich framework with which to express their often-paradoxical experiences and perceptions. The tool may play an important role during the early stages of assessment, history taking, and rapport building; where meaningful dialogue is an essential component of good clinical care. The dialogical characteristics of this instrument are founded on providing caregivers with a non-reductionist description of how their sense of well-being is impacted by illness-related experiences in various domains of life. As indicated, such fore knowledge of life domains impacted by illness could help launch discussion and strengthen the bonds of understanding between caregivers and their patients. Supporting its use as a reliable clinical assessment measure, the internal consistency of S-PRT scales was very strong [67,68], sufficiently so that most were able to meet the stringent .90 standard advocated by Nunnally when the intended use of an assessment device is at the level of the individual [69]. The strong correlation between S-PRT scale scores and endorsement of difficulties coping with illness lend credence to the hypothesized adaptive and motivational role of emotional experience, suggested by Lazarus [70].

Limitations and future directions

A major limitation of this study is the relatively small sample size used to conduct the factor analysis and infer construct validity of the items and respective domains. A typical rule of thumb is that 5–10 respondents are required to specify a stable factorial solution. While the explanatory strength of the factor solution (explaining 83.5% of the pooled variance) using our small sample provides some assurances that the dimensionality of the S-PRT is robust, further confirmatory construct validation is required, preferably using larger samples of patients within particular patient populations of interest.

More research is also required to establish the score ranges and clinical cut-points for the S-PRT scales that could be used to evaluate the sensitivity and specificity characteristics of the measure when identifying people in personal,

interpersonal, or spiritual distress. Data from the current study provides a preliminary hint that a 'normal' emotional balance point may be between 1.3 and 1.8 on a scale from -3 to +3. It is also likely that ideal balance point ranges differ across individuals by disposition, education, and various demographic characteristics. Of related interest, the utility of the S-PRT as an assessment or screening tool needs to be evaluated in various clinical settings. There are also questions as to the impact of completing such a measure on the quality of the relationships formed between patients and their caregivers [71].

Another important issue, particularly for instruments of this type, is its stability versus responsiveness over time and across situations. The low test-retest reliability estimates associated with the Intrapersonal Well-being and Interpersonal Receptivity scales suggest they may be more influenced by recent life events than more firmly held, and thus stable, beliefs about ones' social contributions and orientation to divinity. In fact, the stability of such beliefs, particularly those on the Transpersonal dimensions, may serve to buffer individuals' sense of well-being during times of difficulty and uncertainty. Given the importance of the factors associated with changes in subjective perceptions of well-being and the small number of persons involved in the retest portion of this study, the issue of stability versus situational responsiveness requires further exploration.

Further stem refinement may also be required on the wording of the Transpersonal domain stems. The current wording of the stems may have resulted in the alienation felt by the ten percent of respondents who chose not to complete rating scales in this domain. Written comments from these respondents suggest that they considered themselves to be neither spiritual nor religious and thus chose not to rate these domains. Use of the stem, "My basic beliefs about life and being, help me feel I am:" might provide more encompassing wording; more acceptable to those with an aversion to more traditional religious concepts.

Area of future inquiry should focus on the cognitive skills required for respondents to complete the rating task. The cognitive complexity associated with polar emotional rating scales prove difficult for some groups of patients. Within the focus groups, members with more severe forms of mental dysfunction (e.g., acute psychosis, brain damage or dementia) reported difficulties completing portions of the S-PRT. Specifically, these individuals expressed difficulties forming singular evaluative concepts from using the polarities on the S-PRT scales to rate their life experiences. This may suggest that the methodology may not be well suited to those experiencing acute difficulties forming affective mental abstractions.

Conclusion

The S-PRT provides a unique approach to measurement of individuals' subjective perceptions of meaningful physical, mental-emotional, social and spiritual experiences that occur as a result of illness. The tool may help address a need of health care professionals to assess, and relationally address, individuals' subjective experience of the impact of illness. As a support tool during the qualitative and relational aspects of care, the S-PRT shows great promise. As a research tool, certain aspects of the instrument performed beyond our expectations while other aspects require further refinement, particularly within the context of longitudinal study. Overall, the S-PRT provides a unique methodology for assessing HRQL that integrates two apparently irreconcilable approaches to measurement, the normative-quantitative and the ideographic-qualitative perspectives, into a unified patient-centered approach to subjective HRQL.

List of abbreviations

HRQL: Health Related Quality of Life

PCT: Personal Construct Theory

PGI: Patient Generated Index

PRO: Patient Reported Outcomes

SDM: Semantic Differential Method

SEIQOL: Schedule for the Evaluation of Individual Quality of Life

SF-36: Medical Outcome Study Short Form Health Survey

SIBS: Spiritual Involvements and Beliefs Scale

S-PRT: Self-Perception and Relationships Tool

Authors' contributions

MJA: Principle investigator, co-authorship, study planning, literature review, electronic data collection methods, statistical analyses, manuscript preparation

PMW: Co-authorship, study planning, manuscript preparation

BIW: Research coordinator, recruitment, patient interviews, data collection, manuscript review

JWR: Patient focus group leadership, recruitment, manuscript review

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Research Coordinators

Bushra Wasil MD. PhD (Candidate), Community Health Science, University of Calgary, Calgary, Alberta

Beatrice Breiting BSc, Research Assistant, Calgary Health Region, Calgary, Alberta

Clinical investigators

Cardiology & Hypertension: M. Carducci, RN; C. Gunderson; R. deJong and J. Robertson

Chronic Pain Clinic: P. Taenzer, PhD.

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