

Quality of life and persons with intellectual disability: Can we measure QOL in this population?

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Abstract

Quality of life (QOL) has been discussed by professionals working with persons with intellectual disability (ID) for some time, but since QOL is concerned with subjective well-being, satisfaction and happiness, how is it possible to measure, when the person in question is unable to communicate? Consciousness is believed to be an internal and personal thing, but we have done the simple experiment to ask observers to rate QOL of another person, also in sub dimensions like self-assessed physical and mental health, relationship with self, self-assessed sexual ability, self-assessed social ability, and we have found that people are able to assess the QOL rather accurate of other people. The fact that we are fairly able to read other person's mind and tell their state of consciousness, quality of life and quality of relationships indicate that we are able to share consciousness as an objective phenomenon. As a practical consequence we can measure QOL of people who are unable to communicate allowing us to improve care and make better decisions about life and death. We recommend observer-rated QOL1/QOL5/QOL10 for quality assurance of the medical, psychological or CAM/holistic therapeutic treatments of all patients groups that for some reason, i.e. ID, coma, psychosis, and brain damage has no sufficient language, intelligence, self-insight or ability to rate themselves. We find that the Personal-Development-Q5 (PD5) questionnaire measuring the level of personal developmental in five dimensions: emotions, mind, sexuality, spirituality and I-strength, can also be observer-rated. A strategy for measuring QOL in persons with intelligence deficits (ID) is presented.

Keywords: Quality of life, intellectual disability, mental retardation, assessment.

Introduction

Global quality of life (QOL) means the quality of a person's state of existence. Some people believe QOL to be multidimensional (1), while other researches have found QOL to be about one single dimension like love (2), ability to relate (2), or our fundamental

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sense of coherence (4,5). The more spiritual and abstract the thinking about life is, the more QOL is about a single all-penetrating life-force, like God, the Great Spirit, or the great void (Sunya). The more materialistic the worldview, the more factors are believed to be of relevance. Modern biomedicine often presents the idea that illness and health are multi-dimensional phenomenon with multi-factorial causes.

QOL has been described as well-being, life-satisfaction, happiness, meaning of life, inner balance, self-actualisation, realisation of life's potentials, fulfilment of needs and abilities and functioning in general (6). All these dimensions have been integrated into the theory of integrative quality of life (7), which has been the basis of several QOL questionnaires like the SEQOL (8) and the validated Quality Of Life-Q5 (QOL5) (9) with only five items (see Appendix A). We have found the short QOL5 valid for measuring of global QOL and efficient in documenting the effect of a therapeutic intervention on many different groups of patients (10-15).

The interesting thing for us was, if we can expand this use into measuring the quality of life and treatment effect also of people with intellectual disabilities or other persons with insufficient language or communication skills (16-20). This can only be done if an observer can fill in a QOL questionnaire on behalf of the person unable to communicate. Basically the ability to read/understand, if another person is happy or unhappy is a precondition for successful parenthood. Therefore parents must be able to rate the QOL and mood of their child. We know this ability as empathy, the ability to feel the state of consciousness of other people.

To our knowledge little research has been conducted into the degree of actual knowledge that comes from empathy. Is empathy a true source of knowledge of our fellow men? Are we able, through empathy, to know about other people's emotional and existential states, their thoughts and feelings, their degree of mental, spiritual and sexual development, and their global QOL as the total of all this? And even more interesting: Are we able to tell how the person would rate him or herself, if asked? This might be very different from our rating of the person, as we can use totally different standards, but maybe we even are able to sense the standard use for inner assessment of

QOL and related issues? And are some people better to read people's minds than other? Do we know more about people we love than people we do not care for, meaning that a child that is more loved gets more parental reading and thus more fulfilment of its needs? Are people who chose to be health-professional more empathetic and better to guess than other people?

The present study is not pretending to answer all these questions and we decided for practical reasons to focus on one simple question: Are we able to read the QOL of other people, so that we can monitor the quality of care and the value of interventions in institutions with ID-patients. We asked four simple questions, which we need to know if we are to use Quality Of Life-Q10 (QOL10) and Personal Development-Q5 (PD5) (see Appendix A and B) for observer-rating, giving us the possibility to secure the quality of treatment also for patients with poorly developed or no language, or no actual ability or use of their language due to coma, psychosis, brain-damage or similar reasons:

- Can strangers read each other's QOL including sub-dimensions? Hypothesis I is that empathy gives real knowledge.
- Are people who know each other better to rate the QOL of each other? Hypothesis II is that we develop liking that makes us more empathetic.
- Is it easier to rate the experience of ability than the more abstract and emotional dimensions of quality of relations? Hypothesis III is that ability is more superficial and therefore easier to "see" than the "deeper" existential dimensions.
- Is it more difficult to measure QOL, that is a variable state, than to measure the degree of personal development of the single existential dimensions of body/sexuality, emotions, mind, spirit and I-strength (also called "Ego strength" or "openness of the heart"; a concept often used in existential psychotherapy), which are stable structures of the person? If this is the case, it might be more valuable to practical clinical application to focus on these aspects of life instead of global QOL. Hypothesis IV is that if you

focus on a stable, structural part of man, instead of a more labile state of existence as QOL, extraction of knowledge becomes easier.

Methods

The participants: We asked two groups of people to rate themselves and rate each other and looked statistically at their success of guessing each other's self-ratings. We made the groups in such a way that some of the people were low and other high in the QOL5 and PD5 scores. Group 1 consisted of medical students and therapists with little knowledge of each other and group 2 was medical students and therapists with much knowledge of each other. Both groups consisted of established or future health professionals, who were between 20 to 60 years of age and both genders were represented in the two groups. Only group 2 were familiar with the holistic concepts included in PD5, so only this group were asked to rate

self and other on the D5-questionnaire, that measures the state of human development related to sexuality, emotions, mind, spirit and heart (I-strength) (see table 2). We advertised for medical students at the University of Copenhagen and asked the therapist-students of the Nordic School of Holistic Medicine to participate.

The instruments

The questionnaire called QOL10 consists of the validated questionnaires QOL5 and QOL1, and four questions on self-rated ability (see the wordings in table 1). The QOL10 and PD5 questionnaires are found in Appendix A and B. The participants did not talk together before the test. We did not exclude any data and we reported the results from all groups examined thus avoiding "data fishing". The collected data should in principle, in spite of their scarcity, allow us to test the four hypotheses.

Table 1. The QOL10 consisting of QOL5, QOL1 and four Qs on self-rated ability (see Appendix A for the 5-point Likert scale, and the scoring strategy). Q1, Q2, Q3, Q4, Q5 is from QOL5 (see Appendix A for the score); Q10 = QOL1; Self-rated ability is calculated as the mean of the scores of Q6+Q7+Q8+Q9

-
- Q 1 How do you consider your *physical health* at the moment?
 - Q 2 How do you consider your *mental health* at the moment?
 - Q 3 How do you *feel about yourself* at the moment?
 - Q 4 How are your relationships with your *friends* at the moment?
 - Q 5 How is your relationship with your *partner* at the moment?
 - Q 6 How do you consider your ability to *love* at the moment?
 - Q 7 How do you consider your *sexual functioning* at the moment?
 - Q 8 How do you consider your *social functioning* at the moment?
 - Q 9 How is your *working ability* at the moment?
 - Q 10 How would you assess the *quality of your life* now?
-

Table 2. PD-Q5 - State of human development related to five dimensions: body/sexuality, emotions, mind, spirit and heart (see Appendix B for the Q's and A's)

-
- Q 1 Emotional development: Chronic emotional state
 - Q 2 Mental development: Chronic mental state
 - Q 3 Sexual development: Sexual state
 - Q 4 Spiritual development: Spiritual state
 - Q 5 Development of I-strength: State of heart
-

The options under each PD5-question are quite difficult to understand exactly, and therefore to

answer exactly. It could in theory be quite difficult for people to rate themselves or ask others to rate them

using this instrument. Fortunately the meaning has been intuitively clear by psychotherapists and students of psychotherapy medicine, meaning that using these quite abstract questions have been useful with these groups in spite of this difficulty.

Statistical analysis

We analysed the data using the “single sample t-test”. N was 6 and 9, respectively. A confidence interval for the mean specifies a range of values within which the unknown population parameter, in this case the mean, may lie. It is given by

$$\bar{x} \pm t_{1-\frac{\alpha}{2}, N-1} \frac{s}{\sqrt{N}}$$

where *s* is the sample deviation of the observations and *N* is the number of valid observations. The *t*-value in the formula can be computed with the degree of freedom being *N*-1 and the *p*-value being *1-alpha/2*, where *alpha* is the confidence level and by default is .95. The computation of the confidence interval is based on a chi-square distribution and is given by the formula

$$\left(\sqrt{\frac{(n-1)S^2}{\chi^2_{1-\frac{\alpha}{2}, n-1}}}, \sqrt{\frac{(n-1)S^2}{\chi^2_{\frac{\alpha}{2}, n-1}}} \right)$$

where *S*² is the estimated variance of the variable and *alpha* is the confidence level.

The single sample t-test tests the null hypothesis that the population mean was equal to the given number specified using the option **H0**. The default value in the SAS program used for the analysis for H0 was 0. It calculates the *t*-statistic and its *p*-value for the null hypothesis under the assumption that the sample comes from an approximately normal distribution. It could be argued that the sample size is too small (<30) for this approximation. If the *p*-value associated with the *t*-test is not small (*p* > 0.05), then the null hypothesis is not rejected, and we conclude that the mean is not different from the hypothesized value.

Results

We found the Pearson Correlation (*c*) between self-rated QOL5 and QOL1 to be 0.85 (*p*=0.037), indicating validity of the measured QOL5. We found the Pearson Correlation (*c*) between self-rated QOL5 and PD5 to be 0.88 (significant as *p*=0.0016), and between self-rated QOL1 and PD5 to be 0.86 (*p*=0.0029) strongly indicating that the PD5 is actually a global QOL measure; as the *c*² =0.77 and *c*² =0.74 respectively this indicates that PD5 actually measures the same as QOL5 and QOL1. The PD5 is here validated both by criteria validation against QOL1 and QOL5 and by external observer-rating (see table 5), strongly indicating that the PD5 is also a valid measure for global QOL.

The *P*-values are listed in table 3 (Group 1, QOL10), table 4 (Group 2, QOL10) and table 5 (Group 2, D5). We found that the people in group 1 were good guessers, as 58% of all 10 ratings done by the participants were actually guessed; group 2, where the people knew each other, only guessed 36% of the rating, which was not so good, but still fair. The rating is done on a five point Likert Scale (five alternative answers), and among the participants were people with very high and very low scores; the full scale was used both in self-rating and in observer-rating. With the assumption that all possible responses have the same probability, we have *p*<0.05.

- We thus found Hypothesis I to be confirmed.

When we compared the two groups it was clear that the group of people who knew each other were not better to guess each others ratings than the group of people that did not know each other well.

- We thus found Hypothesis II to be falsified.

When we compared the success rate of guessing QOL5 and QOL1 compared to the four questions of self-rated ability of functioning, we found no difference here.

- We thus found Hypothesis III to be falsified.

When we compared the success rate of guessing the questions of QOL10 with the success rate of

guessing D5, we found that 67% of the D5-ratings were guessed, versus only 36% of the QOL10-ratings in this group.

- We thus found Hypothesis IV to be confirmed.

Table 3. GROUP 1: Medical students and therapists (not acquainted). (Hypothesis: QOL10-self-ratings are different from observer ratings) (p-values > 0.05 signify “participants self-rated score guessed by the group”)

Question	Person 1 (P-value)	Person 2 (P-value)	Person 3 (P-value)	Person 4 (P-value)	Person 5 (P-value)	Person 6 (P-value)	Number of correct guesses
Q1	0.37	0.0001	1.00	0.0705	0.208	0.0001	4 (67%)
Q2	0.004	0.0086	0.0026	0.37	0.37	0.034	2 (33%)
Q3	0.0001	0.089	0.033	1.00	0.0705	0.704	4 (67%)
Q4	0.016	0.025	0.034	0.18	0.0046	0.37	2 (33%)
Q5	0.81	0.18	0.075	0.038	0.18	0.405	5 (83%)
Q6	0.099	0.208	0.0001	0.37	0.18	0.62	5 (83%)
Q7	0.0046	1.00	0.0039	0.089	0.025	0.0046	2 (33%)
Q8	0.62	0.0039	0.0032	0.208	0.0028	0.099	3 (50%)
Q9	0.37	1.00	0.0046	0.089	1.00	0.099	5 (83%)
Q10	0.0039	0.18	0.0004	0.62	0.18	0.18	4 (67%)
QOL5	0.0013	0.103	0.0013	0.017	0.0014	0.52	2 (33%)
Ability	0.20	0.053	0.0007	0.53	0.014	0.24	4 (67%)
Total number of correct guesses (Q1-10)	5	6	2	8	7	7	Mean 5.83 (58.3%)

Table 4. GROUP 2: Medical students and therapists (well acquainted). (Hypothesis: QOL10-self-ratings are different from observer-ratings) (p-values > 0.05 signify “participants self-rated score guessed by the group”). (The symbol “-“ means: cannot be calculated due to structure of/missing data)

Question	Person 1 (P-value)	Person 2 (P-value)	Person 3 (P-value)	Person 4 (P-value)	Person 5 (P-value)	Person 6 (P-value)	Person 7 (P-value)	Person 8 (P-value)	Person 9 (P-value)	No. of correct guesses
Q1	0.015	0.73	-	0.45	0.0331	0.0002	0.020	-	0.080	3 (33%)
Q2	0.0209	0.0209	0.20	0.0001	0.0062	0.35	0.020	-	0.0008	2 (22%)
Q3	0.0066	0.0066	0.35	0.080	0.0001	0.17	0.0062	0.17	0.033	4 (44%)
Q4	0.080	0.080	0.60	1.00	0.080	0.35	0.0016	0.20	0.35	8 (89%)
Q5	-	-	0.0112	0.033	0.080	0.29	1.00	-	0.0008	3 (33%)
Q6	1.00	1.00	0.0001	0.0001	0.020	0.0001	0.0066	0.0001	0.17	3 (33%)
Q7	0.011	0.011	0.0062	0.0011	0.35	1.00	0.0012	0.080	1.00	4 (44%)
Q8	0.0011	0.0011	0.35	0.60	0.45	0.049	0.0001	0.17	0.049	4 (44%)
Q9	0.0001	0.0331	0.17	0.0066	0.00025	0.0072	0.049	0.0062	0.049	1 (11%)
Q10	0.0016	0.0016	0.080	0.0072	0.17	0.17	0.011	0.0025	0.35	4 (44%)
QOL5	0.0092	0.0018	0.0001	0.0001	0.0099	0.0007	0.016	0.78	0.0002	1 (11%)
Ability	0.0014	0.0103	0.0044	0.0003	0.57	0.0015	0.0002	0.0022	0.056	1 (11%)
Total No. of correct guesses (Q1-10)	2	3	6	4	5	6	1	4	5	Mean = 3.6 (36.0%)

Table 5. GROUP 1: Medical students and therapists (well acquainted).
(Hypothesis: PD5-self-ratings are different from observer-ratings) (p-values > 0.05 signify
“participants self-rated score guessed by the group”)

Question	Person 1 (P-value)	Person 2 (P-value)	Person 3 (P-value)	Person 4 (P-value)	Person 5 (P-value)	Person 6 (P-value)	Person 7 (P-value)	Person 8 (P-value)	Person 9 (P-value)	No.of correct guesses
PD-Q1	0.025	0.0025	0.0001	0.033	0.17	0.033	0.104	0.35	0.60	4 (44%)
PD-Q2	0.025	0.1705	0.080	0.17	0.0025	0.35	0.35	0.080	0.0011	7 (78%)
PD-Q3	0.35	0.020	0.0016	0.17	0.0016	0.033	1.00	0.033	0.35	4 (44%)
PD-Q4	0.0062	0.0062	0.020	0.35	0.17	0.35	1.00	-	0.0001	4 (44%)
PD-Q5	0.0016	0.60	0.080	0.35	0.17	0.080	0.080	0.080	0.033	7 (78%)
Mean of PD-Q1-5	0.0025	0.40	0.0005	0.073	0.0092	0.53	0.70	1.00	0.10	6 (67%)
Total number of correct guesses (Q1-5)	1	3	2	4	3	3	5	3	2	Mean 2.9 (58.0%)

Analyzing the data collected with observer-rated QOL10 and PD5

For research in treatment effects and quality assurance you need about 10 patients in each group for a valid test. If you get 30, your statistic analysis will be easier as the Central Limit Theory tells us that the sample means are approximately normally distributed, when the sample size is 30 or greater. For the most reliable measurement of treatment effect you need to measure the patients prospectively, i.e. before and after treatment/intervention and then again after one year. If the treatment is happening over long time you need to measure before treatment and then about three months after treatment start, and then again a year after treatment. If you do it this way, you can measure a change in health that is highly likely to be the effect of your treatment, meaning that you can use the patients as their own control (we call this the Square Curve Paradigm) (21).

The simple way to analyse data is by dichotomising the scale in a “bad” and “well” part. We normally use the bottom values (4 and 5) on the Likert scale as an indication of “bad” and the top part of it (1,2 and 3) as “well”. You include all starting participants in the study. Only patients who comply with the treatment and answer the questionnaire in the end of the study, and report that they are well now, are included in the “cured” group; all the drop outs,

non-responders of questionnaires, and not-cured are treated as not cured. We finally used a statistical table (22) to establish the confidence interval.

The time consumption of administering, collecting and analysing the QOL10 and PD5 were only 10 minutes per person (see Appendix A and B). The QOL10 and PD5 questionnaires are free for all to use (non-commercial use only). The statistics can be made in a few hours and by people with no statistical education.

We found in our study of the treatment effects of clinical holistic medicine (CHM) (10-15) that the following six dimensions measured by the QOL10 questionnaire were of primary interest:

1. Self-assessed physical health (10)
2. Self-assessed mental health (11)
3. Self-assessed QOL (measure with QOL1) (12)
4. Self-assessed sexual ability (13)
5. Self-assessed self-esteem (relation with self) (14)
6. Self-assessed working ability (15)

1) and 2) were the self-assessed physical and mental health, and the average of this corresponded well to the single item questionnaire of self-assessed health (statistical validation of this statement is planned).

Avoiding bias

A simple way of avoiding bias is to make sure that the people, who measure the patient QOL have no interest in the patient getting better. This is a highly utopic demand as there always will be a wish or hope that a treatment works, but this means that if it is possible to make an external team monitor the QOL instead of a local team, this would be better.

Ethical choices

Among the most difficult issues is the choice of terminating a treatment that has no chance of leading to a good result for the patient, but if terminated might lead to the patient's death. The quality of a patient's future life must always be the key issue of concern in this situation.

Discussion

It is important to notice that the two groups were small and non-representative, in spite of great variation in age and gender, QOL and level of personal development. All participants are from Copenhagen and professionally involved in medicine and therapy, and their ability of empathy might be over the average. Nevertheless both groups were great guessers; group two guessed PD5 much better than QOL10, but taken all together the ability to guess was not very different from group 1. To guess 2/3 of 10 self-ratings with 5 different possibilities is not the same as guessing 2/3 of 50 different yes/no alternatives as top and bottom ratings are rare. We need the experiment repeated with more participants in order to learn more.

The two groups contained of people who were all established or becoming health professionals and therefore had fairly much in common. It is a big and unanswered question if empathy and ability to guess falls dramatically, when people are very different from us, i.e. if they have a large intelligence deficit. As relating to these people to some extent can be compared to relating to small children, with no language, we expect that this is not the case. The fact that the members of the second group are acquainted might weaken the argument that this group is actually

“reading” each other, but this argument cannot be raised against the measuring in the first group.

The ability to guess might not relate to empathy at all; if that is the case it is an even larger mystery that our consciousness obviously are shared, and not private at all, in spite of our normal idea of it being so.

We have found that we are able to rate each other's QOL, independently of prior knowledge. We have also found that people who know each other did not guess better. We found that emotional and “deep” existential issues are guessed as easily as the more superficial ability of functioning. We found that if we look directly at the different part of man – body/sexuality, emotions, mind, spirit and heart – it might be easier to rate the developmental states of these than the variable, subjective state of mind reflected in the global quality of life.

QOL10 and PD5 (Appendix A and B) can be used for observer-rated measuring of other people. We find no reason why it cannot be used for rating patients with even a severe intelligence deficit or developmental problem. QOL10 and PD5 (Appendix A and B) can be used for measuring people with ID and for securing the quality of treatment also when the patient cannot speak.

As we do not know if all people have the ability to guess the QOL or personal development of another person, we recommend that the job as observer-rater be given to health professionals. The people measuring QOL do not need to know the patients, so an ambulant team can do this. This also minimize bias, and secure a uniform standard of measuring. As the results seem to indicate that a group statistically guesses better than a single person it will be of value if the observer team consists of three or more persons.

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Appendix A

The QOL10 – a 10 item questionnaire on health, QOL and ability including the validated QOL5 and QOL1 to be used for self- and/or observer rating

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Q 1 How do you consider your **physical health** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad

Q 2 How do you consider your **mental health** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad

Q 3 How do you **feel about yourself** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad

Q 4 How are your relationships with your **friends** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad

Q 5 How is your relationship with your **partner** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad
- 6 I do not have one (This is scored like "5" very bad)

Q 6 How do you consider your ability to **love** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad

Q 7 How do you consider your **sexual functioning** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad

Q 8 How do you consider your **social functioning** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad

Q 9 How is your **working ability** at the moment?

- 1 very good
- 2 good
- 3 neither good nor bad
- 4 bad
- 5 very bad

Q 10 How would you assess the **quality of your life** now?

- 1 very high
- 2 high
- 3 neither low nor high
- 4 low
- 5 very low

The Endpoints you collect are:

1. Self-rated physical health
2. Self-rated mental health
3. Self esteem
4. Quality of relationships with friends
5. Quality of relationships with partner
6. Self-rated ability to love (I-strenght)
7. Self-rated sexual functioning
8. Self-rated social functioning
9. Self-rated working ability
10. QOL1: Self assessed (global) quality of life[7]
11. QOL5: Measured global quality of life[7]
12. QOL10: QOL+Health+Ability/3

To calculate QOL1: Q10

To calculate QOL 5: $((Q1+Q2):2+Q3 + (Q4+Q5):2):3$

To calculate QOL 10 "Health-QOL-Ability":

$([Health] ((Q1 + Q2):2) + [QOL] ((Q10)+(Q3+Q4+Q5):3):2) + [ability] ((Q6+Q7+Q8+Q9):4):3$

The result is comparable to a five point Likert scale of global QOL but more informative. QOL10 is a "global life status", we like to think of this measure as a "subjective sense of coherence(SOC)" measure. We just call the measure "Health-QOL-Ability".

The normal values for Danes for QOL1, QOL5 and QOL10 are around "2" [Ventegodt, S. (1995) *Livskvalitet I Danmark. Quality of life in Denmark. Results from a population survey.* [partly in Danish] Copenhagen: Forskningscentrets Forlag.] (you will see that "2" equals "70%" in the Table if you transform the result to "percent of maximum" as described in [Ventegodt, S. (1996) *Measuring the quality of life. From theory to practice.* Copenhagen: Forskningscentrets Forlag.].

To keep it simple we recommend the use of this scale for comparison:

Q 10 Measured quality of your life:

- 1 very high
- 2 high
- 3 neither low nor high
- 4 low
- 5 very low

Interpretation: 1 is great, 2 is normal, 3 is bad for QOL1 and very bad for QOL5 and QOL10; 4 is very bad for QOL1 and deadly for QOL5 and QOL10; 5 is dying for QOL1, QOL5 and QOL10 - you cannot survive for very long with this low rating.

I would say; if your patients in average are doing worse than QOL1=3 and QOL5= 2.7.5 and QOL10 =2.5 then a significant number of your patients might have severe existential problems and significant suffering.

Appendix B

The Personal-Development-Q5 (PD5) – a five item questionnaire on the level of personal development of sexuality, emotions, mind, spirit and heart (I-strength).. This questionnaire can be self-rated or observer rated

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Q 1 Emotional development: Chronic emotional state

- 1 Vital
- 2 Inhibited
- 3 Blocked
- 4 Frozen
- 5 Dead

Q 2 Mental development: Chronic mental state

- 1 Responsible, mature
- 2 Irresponsible, immature
- 3 Inconsistent and shifting
- 4 Delusioned
- 5 Dissociated, hallucinated

Q 3 Sexual development: Sexual state

- 1 Unblocked, genital (focused on partner)
- 2 Blocked, genital (focused on partner)
- 3 Unblocked, masturbatory (focused on self)
- 4 Blocked, masturbatory (focused on self)
- 5 Infantile autoerotism (no object)

Q 4 Spiritual development: Spiritual state

- 1 Whole, pure intent, loving
- 2 Whole, ambivalent, love and hate
- 3 Whole, autistic (no extrovert intention)
- 4 Split, extrovert
- 5 Split, introvert

Q 5 Development of I-strength: State of heart

- 1 Trusting, I-strong (I-Though)
- 2 Reserved
- 3 Half-hearted (I-Though and I-It)
- 4 Not trusting
- 5 Instrumental, I-weak (I-It)

The endpoints you collect with the PD5 questionnaire are:

Emotional development: Chronic emotional state (Q1)

Mental development: Chronic mental state (Q2)

Sexual development: Sexual state (Q3)

Spiritual development: Spiritual state (Q4)

Development of **I-strength:** State of heart (Q5)

Personal development (**Mean of Q1-Q5**)

To calculate the PD5 score: $(Q1+Q2+Q3+Q4+Q5):5$. Interpretation: 1 is great, 2 is normal, 3 is bad, and 4-5 is very bad.

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