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Original article

The cognitive-spiritual dimension – an important addition to the assessment of quality of life: Validation of a questionnaire (SELT-M) in patients with advanced cancer

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Summary

Questions of meaning and challenge by illness, i.e., the spiritual dimension of quality of life (QL) traditionally played an important role in anthroposophically oriented medicine and have gained importance in palliative medicine and supportive care. In the context of a research project on QL in patients with advanced cancer, we therefore investigated the psychometric properties of a questionnaire covering spiritual QL issues, with the aim of providing a module for the assessment of cognitive-spiritual QL.

Patients and methods: We investigated 89 patients with advanced breast and gastro-intestinal cancer. Construct validity of a modified version of the SELT (Skalen zur Erfassung von Lebensqualität bei Tumorkranken), the SELT-M was tested by multitrait scaling analysis. Discriminant and convergent validity were also tested. The EORTC QLQ-C30 was used as a standard for validation.

Results showed the SELT-M as feasible in administration. Four of the five SELT-M subscales were internally consistent (Cronbach's Alpha = >0.7). The subscale on spiritual QL showed higher within than outside subscale correlations for six of its eight items. Association of the SELT-M with the EORTC QLQ-C30 was good for the items and subscales covering the same aspects of QL in both questionnaires: emotional (Spearman $r = 0.61$), physical functioning ($r = -0.54$) and fatigue ($r = -0.75$). In accordance with expectations, there was no association between spiritual QL with any EORTC QLQ-C30 subscales. Self-assessed spiritual QL in the SELT-M corresponded well with interviewer assessments (test for trend accross ordered groups, $P = 0.0023$).

Conclusions. Overall there is confirming evidence for the hypothesised structure of the SELT-M, especially for the newly developed module on spiritual QL. This module may be used as a module together with other cancer specific QL questionnaires.

Key words: anthroposophical medicine, cognitive-spiritual quality of life, palliative medicine and supportive care, psychometric validation

Introduction

In recent years the traditionally assessed aspects of quality of life (QL) such as physical, psychological and social well-being and functioning have been supplemented by spiritual aspects of QL. Questions of meaning and challenge by illness have become of interest especially in palliative care and chronic illness [1, 2]. Our experience in interviewing patients with advanced cancer has shown that questions concerning the meaning of illness to the individual, religious beliefs and their changes due to illness as well as the striving for spiritual well-being are important issues. So far, some efforts have been made to develop specific questionnaires to assess the spiritual dimension of QL [3–5]. Others have added religious and spiritual aspects to existing QL questionnaires [6]. The aim of these efforts is to better meet the changing QL needs of patients with a life threatening, chronic illness.

In addition to these general considerations in favour of assessing spiritual QL, there have been, encouraged and supported by the Swiss National Foundation for Research, increased points of interaction between conventional and complementary medical schools of thought. In order to make collaborative research efforts in this field possible, it has become necessary to integrate aspects relevant to complementary medicine in QL projects. In anthroposophically extended medicine, for example, QL issues are traditionally not only covered by physical and psychological well-being, social support and coping, but also by cognitive and spiritual processes. In this context, the meaning of illness to the individual's biography is one of the topics in the interaction between treating physicians and patients. Patients are encouraged to find meaning in illness and to come to terms with a life threatening disease by dealing also with questions on death and dying, by accepting illness as part of a larger, cosmic existential development and by taking responsibility for the remaining time on earth [7, 8].

In 1993, the Institute for Medical Oncology of the University Hospital, Berne, and the Lukas Clinic in

Arlesheim, specialised in cancer treatment according to the principles of anthroposophical medicine, have jointly developed a clinical research project on advanced cancer which included a registration study, a randomised study on supportive therapy and a follow-up study. A full description of the project was published elsewhere [9]. The present paper presents results from the first year pilot phase where the feasibility of the project was tested and the methodology for assessing QL was developed. One of the methodological developments was the creation and validation of a questionnaire which would include spiritual aspects of QL. Therefore, a modified version of the existing questionnaire SELT (Skalen zur Erfassung von Lebensqualität bei Tumorkranken [10, 11]) was developed, the SELT-M questionnaire. The SELT was chosen because it adresses in its original version issues of the philosophy of life beside the standard QL aspects. The new module on cognitive-spiritual QL was added in order to cover more extensively aspects of spiritual QL important to anthroposophical medicine. The aim of the present investigation was to test psychometrically the newly created module.

Patients and methods

Patients and data collection procedures

Continuous patients with metastatic, locally advanced or non resectable breast or gastro-intestinal cancer either newly diagnosed or admitted to the two clinics were investigated. These diagnostic groups were chosen because they were the most frequently treated diagnoses at the institutions where the 'parent' study was conducted. The data collection period and hence sample size were predetermined by patient availability during the one year pilot phase. Sociodemographic and medical data were collected at baseline and the patients who consented were asked to fill in a set of self-assessment QL questionnaires. In addition, a semi-structured interview on physical, psychological, social as well as cognitive-spiritual aspects of QL and coping was carried out. With one exception (coping questionnaire), the questionnaires were handed to patients after the in-person interviews for completion at home. Performance status and medical data were collected from the medical records, all other data from patients themselves.

Quality of life instruments

The SELT [11], a QL questionnaire with several subscales on the subjectively perceived physical, psychological and social well-being as well as the general orientation in life, was modified to include spiritual QL and exclude aspects such as physical symptoms which were covered in the other concurrently used instruments. Eight items of spiritual and cognitive QL (subscale SPIRITUAL) were added to the SELT. These items cover themes such as the meaning of illness to the individual, finding calmness and composure about being ill and thoughts about death and dying (see Appendix for full wording, items 16–23). They were developed by two anthroposophically trained physicians (P. Heusser, S. Helwig) on the basis of their clinical experience at the Lukas Clinic and their theoretical background. The new items were formulated in accordance with the rules for test construction stated by Streiner and Norman [12]. Because most of the questions indicate a directional process, negative poling of the questions would have indicated the reverse process and hence was used only in one case in the SPIRITUAL subscale. The subscales 'Subjective physical well-being' (SUBPHYS, three items), 'Basic mood' (BASMOOD, six items), 'Perceived social support' (PERCSUP, three items) and 'General philosophy of life' (GENPHIL, three items) and an item of overall QL were retained from the original SELT version (see Appendix). The modified version of the SELT (SELT-M) hence consisted of 24 items with five scoring possibilities (from 'not at all' to 'entirely so', scores 1–5) to answer the question 'How much does this statement apply to you?' Scores were recoded in such a way that higher scores meant better QL for all items.

In addition to the SELT-M, the EORTC QLQ-C30 (Quality of life Questionnaire of the European Organisation for Research and Treatment of Cancer) was also filled out [13]. The official German translation of the EORTC QLQ-30 was used as a standard measure [14–18] against which the SELT-M items and subscales were tested psychometrically.

In a semi-structured interview patients were furthermore asked in person about cognitive-spiritual aspects of QL. A four point categorical scale was used by the interviewer to rate the extent to which patients found meaning in their illness, saw positive aspects in illness and were able to find activities helpful in coming to terms with illness. Classifications from the question on the meaning of illness were grouped into a dichotomous variable for additional comparison to the self-assessments from the SELT-M SPIRITUAL subscale.

Statistical analysis

The original scoring procedures specified by the authors were used for the EORTC QLQ-C30 and where possible for the SELT-M. Subscales were calculated only when all items of a subscale were answered. Internal consistency of the subscales of the SELT-M was tested by Cronbach's Alpha. Item intercorrelations within the SELT-M and between SELT-M and the subscales of the EORTC QLQ-C30 were determined by Spearman correlation coefficients to test construct validity. Where appropriate, Fisher's exact test was used to test association. Criterion validity was assessed by test for trend across ordered groups [19]: interviewer classifications of patients' cognitive-spiritual QL were used as the outside criterion.

The hypothesised structure of the new SELT-M subscale on cognitive-spiritual QL was investigated by multitrait scaling analysis, even though the sample size for this analysis was rather small. To check whether selected individual items could be aggregated into the hypothesised set of multi-item scales, multitrait scaling was based on a matrix of item-intercorrelations (Spearman Correlation Coefficient). All items of the hypothesised multi-item scale were correlated with each of the total, including their own (corrected for overlap). Evidence of item convergent validity was defined as $r > 0.4$ between an item and its own subscale. Support for item discriminant validity was based on a comparison of the magnitude of the correlation coefficient of an item with its own subscale as compared with other subscales. Scaling success was defined in those cases in which an item correlated higher with its own (corrected for overlap) than with another subscale [20]. P-values were from two-sided tests. All data was analysed by STATA.

Results

Medical and sociodemographic characteristics

Of the 89 patients investigated, 49 had breast and 40 gastro-intestinal cancer. Fourty-two patients were seen in Berne; 47 at the Lukas Clinic. Median age of the pilot phase population was 55 years, 56% of gastro-intestinal patients were men: There were comparatively more men at the University hospital than at the Lukas Clinic (65 vs. 49%, Fisher's exact test, $P = 0.053$). 69% of patients were married; 75% had children; 21% lived alone. 25% of patients had primary, 54% secondary and 21% college

education. Performance status at study entry was very good (ECOG score = 0) in 20% of patients; 59% had an ECOG score of 1–2, and 21% had low performance status (ECOG = 3). These performance scores were also reflected in QL. While mean values for physical, emotional, cognitive and social functioning in the EORTC QLQ-C30 were similar in our population to the values for elderly and aids patients [16, 21], our cancer patients showed much higher values on pain and fatigue (see Table 3).

Feasibility

Eighty-nine of 107 (83%) sets of questionnaires handed out in total were returned with very few missing items. The main reason for non-compliance was physical condition (ECOG performance higher than 2). None of the patients interviewed on their impressions in filling in the SELT-M stated any difficulties in completing the questionnaire with the exception of one item (No. 20) containing a double negation. This item was subsequently reworded to make it more readily understandable. Out of the 2136 (89 × 24) items which should have been completed by 89 patients who returned the SELT-M, 83 items were missing and 2053 items were complete (96%). There seemed to be no 'yes-saying' tendency, as the consistent answers to differently polarised items showed.

Internal consistency of the SELT-M subscales

Table 1 shows the Cronbach's Alpha Coefficients for the SELT-M subscales. The Cronbach's Alpha values were >0.7 for all but one subscale on perceived social support (PERCSUP) consisting of three items. Analysis by institution showed no difference in internal consistency on any of the subscales of the SELT-M. The newly developed subscale showed an equally adequate internal consistency as the other subscales.

Table 1 Descriptive data and internal consistency for SELT-M subscales.

SELT-M subscales	Number of items	*n*	Mean (score 1–5)	SD	Median	Cronbach's Alpha Coefficient
Subjective physical (SUBPHYS)	3 (1–3)	90	2.5	1.0	2.3	0.70
Basic mood (BASMOOD)	6 (4–9)	86	3.6	0.8	3.8	0.78
Subjective social (PERCSUP)	3 (10–12)	87	4.0	0.7	4.0	0.36
Orientation in life (GENPHIL)	3 (13–15)	85	3.4	0.9	3.3	0.73
Cognitive/ spiritual (SPIRITUAL)	8 (16–23)	79	3.6	0.7	3.5	0.73

Table 2. Item correlation analysis, SELT-M scales (Spearman Corr. Coeff.).

SPIRITUAL	S16	S17	S18	S19	S20	S21	S22	S23
S17	0.42	1						
S18	0.30	0.46	1					
S19	0.36	0.49	0.42	1				
S20	0.10	0.07	0.01	0.05	1			
S21	0.32	0.35	0.18	0.38	0.01	1		
S22	0.19	0.22	0.13	0.20	0.14	0.16	1	
S23	0.50	0.34	0.19	0.11	0.19	0.59	0.08	1
SPIRITUAL	0.71	0.68	0.53	0.64	0.28	0.62	0.43	0.66

Multitrait scaling analysis of SELT-M items and subscales

Table 2 shows the item-intercorrelations of the SPIRITUAL subscale. With the exception of items 20 and 22, intercorrelations of SPIRITUAL were generally satisfactory. Item intercorrelations of $r > 0.4$ within subscales were most frequent in the SPIRITUAL (especially items 16 to 19 and 23), compared to the other subscales (numbers not shown). Five out of the eight SPIRITUAL subscale items showed correlation values of above $r = 0.60$ with their subscale.

The items of the SPIRITUAL subscale showed substantially higher correlations, corrected for overlap, (range $r = 0.28$ for item 20 to $r = 0.71$ for item 16) with their own subscale than with any of the other four subscales (range $r = -0.16$ for item 17 with SUBPHYS to $r = 0.39$ for item 16 with GENPHIL, detailed results not shown).

SELT-M and EORTC QLQ-C30

Cognitive-spiritual QL (SPIRITUAL) items showed low correlations ($r < 0.40$) with the items of the EORTC QLQ-C30 (data not shown). Table 3 shows the subscale correlations between EORTC QLQ-C30 and SELT-M. Again, in accordance with expectations, the subscale on cognitive-spiritual QL (SPIRITUAL) of the SELT-M does not correlate with any of the EORTC QLQ-C30 subscales.

The subscales on physical functioning and basic mood of the SELT-M correlated well with almost all of the EORTC QLQ-C30 subscales, whereas the other SELT-M subscales were, with the exception of GENPHIL with emotional functioning, not correlated.

Item by item correlations higher than 0.40 between EORTC QLQ-C30 and SELT-M items were present for 10 of the SELT-M items (detailed results not shown): All three items of the subscale on physical well-being (SUBPHYS) and the item on general QL correlated highly with several EORTC QLQ-C30 items of the subscales on physical functioning, fatigue, emotional functioning, pain and general QL. The SELT-M items on sadness and anxiety, anger and joy in life (subscale BASMOOD) as well as items 13 and 14 (subscale GENPHIL) correlated with the emotional functioning

Table 3. EORTC QLQ-C30 and SELT-M subscales correlations.

EORTC QLQ-C30 subscales	*n*	Mean (stddev) of EORTC	Spearman Correlation Coeff. SELT-M and EORTC QLQ-C30 subscales				
			SUBPHYS	BASMOOD	PERCSUP	GENPHIL	SPIRITUAL
Physical functioning	87	42.3 (28.1)	−0.54	−0.38	−0.27	−0.11	−0.04
Role functioning	86	18.6 (28.7)	−0.42	−0.19	−0.17	−0.20	−0.02
Emotional functioning	84	59.5 (25.1)	0.46	0.61	0.27	0.46	0.02
Cognitive functioning	85	70.8 (27.9)	0.40	0.45	0.29	0.29	0.08
Social functioning	88	65.0 (31.1)	0.57	0.45	0.28	0.24	−0.09
Quality of life	90	55.1 (21.7)	0.71	0.57	0.28	0.35	0.06
Fatigue	90	57.3 (31.3)	−0.75	−0.51	−0.38	−0.24	0.13
Nausea and vomiting	90	15.7 (26.2)	−0.46	−0.42	−0.26	−0.22	−0.09
Pain	89	43.6 (33.1)	−0.49	−0.21	−0.02	−0.08	0.19

and general QL items (Spearman r = 0.40 to 0.67). The SELT-M item on boredom was, however, more weakly associated with emotional functioning (r = 0.33). None of the items of the two subscales on social relations (PERCSUP) showed the required correlations ($r > 0.40$) with any items of the EORTC QLQ-C30.

SELT-M SPIRITUAL subscale and interviewer classification

The median of the scores of the SPIRITUAL subscale items was compared to the classification given by interviewers for the cognitive-spiritual QL dimension. From the interview, the question on the meaning of illness to the patient was taken as a reference indicator for cognitive-spiritual QL. SELT-M questionnaires and corresponding interview classifications were available from 78 patients.

Table 4 shows that the lower the cognitive-spiritual QL was classified in the interview, i.e., the less meaning patients perceived in their illness, the lower the scores of the SPIRITUAL subscales in the SELT-M were (test for trend across ordered groups: P = 0.0023). When the interview classification was converted into a dichotomous variable, with 'no' indicating that patients perceived no meaning in illness and 'yes' indicating that patients saw illness as meaningful for their life and biography, the correspondence with lower and higher scores in the SELT-M was confirmed (Wilcoxon test P = 0.0003).

Table 4. SELT-M subscale on cognitive-spiritual QL grouped by interview classification.

SELT-M	Extent of cognitive/spiritual QL in interview as classified by interviewer; Median, score range 1–4 (*n*)				
	No	Rather no	Rather yes	Yes	*P*-value
SPIRITUAL	3.2 (28)	3.4 (6)	3.8 (25)	4 0 (19)	0.0023[a]
SPIRITUAL	3.3 (34)		3.9 (44)		0.0003[b]

[a] Test for trend accross ordered groups [21].
[b] Wilcoxon test [22].

Discussion

We found good evidence for the construct and discriminant validity of the newly created subscale SPIRITUAL on cognitive-spiritual QL as well as for the other SELT-M subscales. The SELT-M was easily administered and filled out by patients as shown by the relatively few missing questionnaires in a population of severely ill cancer patients. In addition, in the completed questionnaires, there were very few missing items. Even the questions of the SPIRITUAL subscale on death and dying were readily answered by patients.

Internal consistency of the subscales was good with the exception of the subscale on perceived social support which tries to cover widely diverse aspects of social well-being in only three items. One item covers the concept of alienation from others, the second one the extent to which patients talk about illness with their loved ones and the third one addresses the functional status making the acceptance of help from others necessary. It is therefore not surprising that these three items were not answered consistently. It may well be that patients have no problems in talking in their family about illness but find it very burdensome to become dependent on them for carrying out their daily activities. In future use of the SELT-M the social subscale questions should therefore be treated as single items.

Even though some of the item-intercorrelations within the SPIRITUAL subscale were not high, the SPIRITUAL items were also not highly correlated with items of other subscales, with one exception. There was more overlap of association between the original SELT subscales (especially the ones on the general philosophy of life and basic mood and subjective physical well-being) than between these subscales and SPIRITUAL. In summary, this shows that SPIRITUAL assesses an aspect of QL not previously covered in the SELT, and hence that SPIRITUAL provided a valuable addition to the questionnaire.

Association of SELT-M with the standardised and psychometrically well tested EORTC QLQ-C30 was present for those items and subscales where the two questionnaires overlapped in content, namely emotional functioning and general quality of life. Association was

expected to support construct validity, i.e., for emotional and physical functioning as well as general QL. Discriminant validity of the SELT-M was evident from comparisons with EORTC QLQ-C30 subscales not covered by SELT-M. The subscale on spiritual QL (SPIRITUAL) was not associated with any of the EORTC QLQ-C30 subscales which indicates that it measures an aspect different from the ones covered in the EORTC QLQ-C30. By assessing the cognitive-spiritual aspects of patients' way to come to terms with illness, something unique is being measured which is not covered in other QL questionnaires placing emphasis only on psychological, physical and social aspects of QL. The subscale on spiritual well-being also does not show any association with any of the other subscales of the SELT-M, hence indicating that it measures also within the SELT-M itself an independent aspect of QL. The excellent correspondence between patients' own assessment of their cognitive-spiritual QL and the judgement of the interviewers provided further evidence for construct validity and showed that the study of spiritual issues is feasible in patients with advanced disease [22].

Whereas traditional QL questionnaires focus on the assessment of problems or their absence, the cognitive-spiritual QL aspect in the SELT-M has as its basic idea that illness changes the patient's QL but these changes must not necessarily be problematic. They may also offer opportunities for dealing with unresolved issues in a person's life and thus contribute to the overall biographic development. What is assessed with the cognitive-spiritual subscale of the SELT-M is therefore the outcome of a process of personal change (or in case of a low cognitive-spiritual awareness, the absence thereof). This makes the SPIRITUAL SELT-M subscale well suited to study changes due to psychological and medical interventions or complementary medical treatment such as anthroposophic medicine. It may be used as a module on cognitive-spiritual QL together with other more generic questionnaires.

In conclusion, overall there is confirming evidence for the hypothesized structure of the the newly developed subscale on cognitive-spiritual QL, hence giving clinicians the opportunity to capture an aspect of QL important to patients but otherwise seldom taken into account. Further study beyond a single baseline assessment is needed to show the SPIRITUAL subscale's sensitivity to change in longitudinal study designs.

Appendix – Text of SELT-M questionnaire

	Wie stark trifft diese Aussage für Sie zu?	How much does this statement apply to you?
1	In den vergangenen Monaten hat es mich stark belastet, dass ich die Krankheit stark spüre	In the past months, I felt the burden of illness very strongly
2.	In den letzten Wochen fühlte ich mich oft müde und erschöpft	In the past weeks, I often felt tired and exhausted
3.	Zur Zeit erlebe ich meinen Körper als so belastbar und leistungsfähig wie eh und je	At the moment, I experience my body as just as effective and capable as ever
4.	In den letzten Wochen konnte ich oft Glück empfinden	In the past weeks, I was often able to experience happiness and joy
5.	Wenn ich zurückdenke, war ich in den vergangenen Tagen und Wochen oft traurig	Thinking back to the past days and weeks, I felt sad much of the time
6.	Vieles, was ich in den vergangenen Tagen und Wochen gemacht habe, war für mich eintönig und langweilig	Many things I did in the past days and weeks were boring and monotonous to me
7.	In den vergangenen Tagen und Wochen war ich oft ängstlich und unsicher	In the past days and weeks, I often felt frightened and insecure
8.	In den letzten Tagen und Wochen stieg öfter Wut in mir auf	In the past days and weeks, feelings of anger kept creeping up in me
9.	Im allgemeinen war ich in den letzten Wochen guten Mutes und voller Lebensfreude	In general, I was in good spirits and full of joy during the past weeks
10.	Auch in der Familie und im Freundeskreis überkam mich in den letzten Wochen manchmal ein Gefühl von Einsamkeit	Even with my family and friends, I was at times overcome by feelings of loneliness in the past weeks
11.	In den vergangenen Wochen konnte ich sehr gut mit mir nahestehenden Personen über wichtige Dinge sprechen	During the past weeks, I could talk very well about important things to the people close to me
12.	In der vergangenen Zeit hat es mich belastet, dass ich auf die Hilfe anderer angewiesen bin	I felt burdened a lot lately by my dependence on the help of others
13.	Schon lange verspüre ich in meinem innersten Kern Ruhe und Gelassenheit	Feelings of calm and composure have prevailed in my innermost being
14.	Ich sehe heute viele Dinge in einem positiveren Licht	Today, I see many things in a more positive light
15.	Ich habe Halt in einem festen Glauben/einer festen Lebensorientierung gefunden	I have found comfort and stability in religion/in a philosophy of life
16.	Ich habe neue, wertvolle Erfahrungen gemacht, die ich ohne meine Erkrankung nicht hätte gewinnen können	Thanks to my illness, I was able to make valuable experiences I would not have gained otherwise
17.	Ich kann das Wesentliche vom Unwesentlichen besser unterscheiden	I am better able to separate essential from non-essential matters
18.	Es bereitet mir weniger Mühe, mit den Fragen nach Leben und Tod umzugehen	I have to make less of an effort lately to deal with questions of death and dying
19.	Ich habe heute mehr Mut, mich selber zu sein	I feel more courageous to be myself
20.	Es gelingt mir besser, neue Interessen zu entwickeln	I am better able to develop new interests
21.	Ich habe neue Hoffnungen entwickelt, die über den Bereich der bloss körperlichen Krankheit hinausgehen	I have developed new hopes surpassing the dimension of my physical illness
22.	Es fällt mich schwer, in meiner Krankheit einen positiven Sinn zu sehen	It is difficult for me to see positive meaning in my illness
23.	Ich habe neue Ziele für mein Leben finden können	I have found new goals in my life
24.	Wie würden Sie ganz allgemein Ihre Lebensqualität einschätzten?	Generally speaking, how would you rate your quality of life?

Pretesting of English translation is required before use in English speaking patients.

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