Measuring the quality of life of cancer patients with

The Rotterdam Symptom Checklist (RSCL)

A manual

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Preface

The large increase in the number of social science studies addressing health-care related subjects has led to the development of numerous instruments for measuring concepts like health, social support, functional status, and quality of life. However, the wide range of instruments that has become available, presents researchers with several problems. In the first place, the lack of information on the psychometric properties of some instruments makes it difficult to assess the quality of a questionnaire. Furthermore, it is not always clear to what extent a (theoretical) domain is covered by the existing instruments. Uncertainty about the comparability of questionnaires hampers comparison of results across studies. The task researchers face whenever they have to select an appropriate measuring instrument can be quite daunting.
Additional confusion is created by the many different versions that exist of some questionnaires. It may prove hard to ascertain which version is the original one, and which versions are adaptations, made intentionally or not, of the original questionnaire.

Researchers of the Northern Centre for Healthcare Research (NCH) frequently encounter the above problems at the start of a new study. In order to help them resolve these problems the NCH has decided to publish a series of manuals on the measuring instruments used in NCH research. Some of the instruments have been developed by the NCH, others are existing instruments. The objective pursued by publishing the series is threefold. *Firstly*, the manuals provide information, e.g. instructions on how the questionnaires should be scored, and descriptions of the basic psychometric properties of the instruments. *Secondly*, the series aims to stimulate utilization of particular instruments, preferably identical versions of them, thus facilitating comparison of the results of different studies. *Thirdly*, the series will enable researchers who wish to use a different instrument, or who decide to develop a new one, to make a well-considered choice.

As the instruments included in the series are being used in new studies, additional information will continuously be generated, e.g. concerning validity and reliability, or the development of standard scores. Furthermore, an instrument may need to be adapted to new insights. The users of the series will be kept informed of any new developments pertaining to the instruments. Whenever important supplementary information emerges, a revised edition will be published.
Finally, users should take notice of the following. Several rules, which may vary from instrument to instrument, should be observed when using the instruments presented in the series. We request you to carefully read the ‘Permission for use of the RSCL’ on page 35.

R. Sanderman PhD

On the second edition

The name of the institute has been changed, as well as the ‘permission for use of the RSCL’.
With that the old permission rules are cancelled.

Juni 2012,

Prof. R. Sanderman PhD
F.L.P. van Sonderen PhD

Contents

Acknowledgement

I would like to thank, in the first place, Jean Pruyn and Ferd van Knippenberg. Without their original work and our stimulating debates, the RSCL would not have been developed and used over such a long period. Secondly, I would like to acknowledge Jan Neyt. As he initiated the first quality of life study in the Netherlands, the instrument was developed thanks to him. Finally, I am grateful for Anita Legtenberg's preparation of this manual.

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1 Introduction

Over the past decades the importance of investigating the quality of life of cancer patients has been stressed increasingly. Quality of life is regarded as a subjective report of the patients' experience of disease and treatment. Assessing quality of life is meant to

1) enhance the insight into the consequences of the disease and its treatment,
2) indicate groups of patients at risk for developing high levels of distress, and
3) enable the comparison of the effectiveness of different treatment modalities or care programs, and thus support decision making in clinical oncology.

An instrument to assess quality of life must in the first place cover the relevant content: the concept to be measured. Quality of life is generally considered to be a multidimensional concept. In their review of instruments, Moinpour and colleagues (Moinpour et al., 1989) have suggested that the inclusion of a physical and a psychological domain is to be considered a minimal requirement for quality of life assessment in cancer patients. Cella and Tulsky (1990) have advocated a three dimensional approach, in line with the WHO definition of health. In such an approach a physical dimension, covering the functional status and physical symptom experience, an emotional dimension and a social dimension are distinguished. De Haes and others (De Haes et al., 1992) have advocated the addition of an overall measure to assess quality of life as well. Such global valuation has been described as encompassing the evaluations of specific dimensions or attributes in an overall way.

In the context of clinical trials repeated measurement requires assessment forms which are easy to handle for clinicians, nurses and datamanagers. Moreover, compliance of patients, especially when ill, will be enhanced if an instrument is easy to complete and short.

1.1 Rotterdam Symptom Checklist, the history and development

One instrument to measure the quality of life of cancer patients is the Rotterdam Symptom Checklist (RSCL). The RSCL was originally developed as a tool to measure the symptoms reported by cancer patients participating in clinical research. It soon proved applicable to monitor the levels of the patients' anxiety and depression and the presence of psychological illness (Trew & Maguire, 1982).

The RSCL was constructed on the basis of secondary analyses of the data from three studies done with different checklists (Pruyn et al., 1980): 1) the Hopkins Symptom Checklist, which was used in a population of 352 psychiatric patients, 147 patients with rheumatoid arthritis, and 308 'normal' controls (Luteijn et al., 1979), 2) a symptom checklist used in a study on the symptoms of 150 breast cancer patients (Linssen et al., 1979), and 3) a Dutch version of the Symptom Distress Scale developed by McCorkle and Young (McCorkle & Young, 1978) applied to a group of 49 hospitalized cancer patients (Leendertse et al., 1979). The selection of items from these checklists was based on factor loadings, relevance according to a group of experts in oncology, and the distribution of answers. This process resulted in an item list comprising physical and psychological symptoms. Patients were asked to indicate the degree to which they had been bothered by the indicated symptoms over the past three days, on four-point, Likert-type rating scales. Items referring to the activities of daily living were added to cover the patients' functional status. One item regarding the overall evaluation of life quality was added later. On the basis of the early validation studies four items were deleted (De Haes et al., 1990).

An instrument should have adequate psychometric properties. This means it should be reliable as well as valid. As part of the validity of quality of life instruments the sensitivity to changes occurring as a result of clinical events, i.e. clinical validity, needs to be established (Hays et al., 1992).

The RSCL was validated originally in a Dutch study (De Haes et al., 1983) and since then has been used in a number of Dutch and British investigations (Hopwood, 1984; De Haes & Welvaart, 1985; Fallowfield et al., 1986; Morris & Royle, 1988). These also provided evidence for its ease of application.
Further validation studies have substantiated the reliability and validity of the RSCL in the Netherlands, Italy, the United Kingdom and Portugal (De Haes et al., 1990; Paci et al., 1992; Watson et al., 1992; Dos Santos et al., 1994). On the basis of its feasibility and validity the use of the RSCL was advocated in clinical research (Maguire & Selby, 1989) as well as cost-effectiveness studies (Uyl-de Groot et al., 1994).

As a result of early dissemination of the RSCL and the decision not to impose copyright on its use, different versions of the instrument have been used in different studies and countries. This process has sometimes led to confusion about the version to be taken as a starting point as well as about scoring rules. Therefore, we have decided to publish a manual to serve as a basis for dissemination, adaptations and scoring. In the present manual the use of the RSCL is described and scoring rules are given. Also, an overview of what is known regarding the psychometric qualities of the instrument is presented. Finally, to enable comparison, 'norms' are given for different disease-, treatment- and culture-related conditions.

2 Description of the RSCL and instructions

2.1 Content of the RSCL

Content of scales and subscales

The RSCL is a self-report measure to assess the quality of life of cancer patients. The RSCL was designed to cover, originally, 4 domains: physical symptom distress, psychological distress, activity level and overall global life quality. These form the main scales. The items regarding psychological distress have been interspersed among the items regarding physical distress in order to avoid response sets in the first place. Also, the possibility of inducing distress by putting together all psychological symptoms has served as an argument. On the basis of factor analyses presented in the current manual and earlier, more specific subscales within the physical symptom distress experience can be constructed in some studies (De Haes et al., 1990; De Haes et al., in preparation). An overview of subject headings and number of items in the main scales is given in Table 1. More specific subscales are referred to later (see chapter 3.3).

The items constituting the main scales in the RSCL are given in Table 1.

The **physical symptom distress** scale consists of 23 items referring to different physical symptoms. Some symptoms such as headaches or fatigue, may be experienced by people in general as well as by cancer patients. Other symptoms are more specifically to related to cancer or cancer treatment: e.g gastro-intestinal and chemotherapy related symptoms. The items constituting the physical symptom subscale are given in Table 2.

The **psychological distress scale** consists of 7 items regarding different symptoms that may be experienced by cancer patients as well as in other populations. None of these items refers to psychological symptoms that might be considered 'psychosomatic' (e.g. headaches or sleeping problems). The item loneliness or feeling lonely was omitted earlier on the basis of skewed distribution. Moreover, it has been decided that concentration included earlier is no longer part of the psychological distress subscale. The 'concentration' item has been excluded from the psychological distress subscale as it proved less clearly related to psychological distress. It turns out to be linked to physical distress, notably fatigue (see Table 4). With concentration omitted from the psychological distress scale, none of the psychological symptoms then has an explicit physical component (Plumb & Holland, 1977). Moreover, in British studies the version without the item concentration turned out to indicate clearly the absence or presence of psychological morbidity [1].

The **activity level scale** consists of 8 items regarding functional status. These items form a scale in which mobility as well as social and role activities are covered. The scale is not related to cancer specifically. In some populations, like the elderly, the last item: 'go to work' may not be relevant for any respondent. If so this item may have to be omitted from the questionnaire. Also it must be noted that in some populations, especially in breast and gynaecological cancers the item is not applicable for many women. Two solutions are available: either substitution (see par. 2.2) or transformation over seven items.

The **overall valuation of life** (sometimes called either global quality of life or overall quality of life) is measured by one single item included in the checklist. The item is derived from research in the quality of life of the population in general. An affective operationalisation was chosen for this item as such approach proved, in line with theory, more sensitive to clinical change (De Haes et al., 1992).

Response categories

For most items responses are given on 4-point Likert-type scales. For the patients' symptom experience of both physical and psychological distress responses range from 'not at all' to 'very much'. For the activity level scale responses range from being 'unable' to perform an activity up to being able to do so 'without help'. An example is given to instruct the respond-

Table 1

Content of items of four main scales in RSCL

physical symptom distress (23 items)		psychological distress (7 items)	
s1:	lack of appetite	s2:	irritability
s3:	tiredness	s4:	worrying
s5:	sore muscles	s6:	depressed mood
s7:	lack of energy	s9:	nervousness
s8:	low back pain	s11:	despairing about the future
s10:	nausea	s17:	tension
s12:	difficulty sleeping	s19:	anxiety
s13:	headaches		
s14:	vomiting		
s15:	dizziness		
s16:	decreased sexual interest		
s18:	abdominal (stomach) aches		
s20:	constipation		
s21:	diarrhoea		
s22:	acid indigestion		
s23:	shivering		
s24:	tingling hands or feet		
s25:	difficulty concentrating		
s26:	sore mouth/pain when swallowing		
s27:	loss of hair		
s28:	burning/sore eyes		
s29:	shortness of breath		
s30:	dry mouth		

activity level (8 items)		overall valuation of life (1 item)	
act1:	care for myself (wash etc.)	all1:	all things considered
act2:	walk about the house		
act3:	light housework/household jobs		
act4:	climb stairs		
act5:	heavy housework/household jobs		
act6:	walk out of doors		
act7:	go shopping		
act8:	go to work		

ent about answering the question (please note that 'a little' is circled in the instruction, see Appendix). The overall valuation of life is assessed on a seven point Likert-type scale, as is usual in the literature regarding the population at large from which the question was derived. Answers range from 'excellent' to 'extremely poor'.

Experienced distress

In quality of life questionnaires the experience of symptoms or complaints can be formulated either in a (dys)function mode (e.g. is the patient constipated?) or from the experienced burden perspective (e.g. to what extent is the patient bothered by constipation). In the RSCL the level of symptom experience is formulated in an experienced distress mode. The respondent is asked to what extent they are bothered by the symptom mentioned (see note 1). In the activity level scale a functional approach is followed. Respondents are asked to what extent they are able to perform activities.

Time frame

Originally, the RSCL was chosen to cover 'the past three days'. This time frame has been changed to 'during the past week'. The decision to opt for somewhat longer period was based on the wish to cover more fully the presence of side effects while remaining within the time span easily remembered by the patient. Moreover, although longer periods of time have been found to result in a stronger relation between symptom reporting and 'complaining tendency' or neuroticism, this tendency to report or experience physical distress on the basis of personality characteristics rather than on the basis of external influences is still less evident when asking questions over a week (Linssen et al., 1982).

Table 2

Summation of item scores to compute scales

physical symptom distress level =	sum of physical symptom scores (s1+s3+s5+s7+s8+s10+s12+s13+s14+s15+s16+s18+s20+s21+s22+ s23+s24+s25+s26+s27+s28+s29+s30): range = 23 to 92
psychological distress level =	sum of psychological symptom scores (s2+s4+s6+s9+s11+s17+s19): range = 7 to 28
activity level impairment* =	sum of activity level items act1+act2+act3+act4+act5+act6+act7+act8
overall valuation of life* =	all1 range = 1 to 7

* When reversing the activity level and overall valuation of life scale for reasons of consistency the scoring will be 32-(act1+act2+act3+act4+act5+act6+act7+act8) and 1-all1 respectively.

2.2 Scoring and analysis

Scoring of items and (sub)scales

The scoring of items is straight forward: ranking from the left (first to the right) 4th column. Thus scores given in the RSCL Symptom Checklist are 1 (not at all), 2 (a little), 3 (quite a bit), 4 (very much). In other words: the higher the score, the higher is the level of burden or impairment [2].

The activity level items are, likewise, scored from 1 to 4. The level of dysfunction in these items is, as a result, negatively related to the score height: the higher the score, the better the function. The same is true for the quality of life item scores range from 1 (excellent) at the top to 7 (very poor) at the bottom. Scores for the activity level scale and the overall valuation can be reversed in order to achieve ratings for the different indicators which are all in the same direction. Obviously, this should be mentioned. Scale scores are obtained by summating scores of individual items. The computation is given in Table 2.

Standardization of scoring

It is possible to standardize the scores of scales by transforming raw scores into scores on a 100-point scale in a systematic way. This makes results more easily interpretable. Moreover, the level of quality of life impairment in the different scales can be compared more easily. In such a scale 0 implies a level of no impairment, 100 implies the highest level of impairment. The way to transform scores is given in the following formula:

$$\frac{\text{raw scale score - minimum raw score}}{\text{maximum - minimum score}} \times 100 = \text{transformed score}$$

For example: suppose someone has a raw score of 14 on the psychological distress scale. Since the scale score is calculated by summing 7 items, the range is 7 to 28. This would imply that the transformed score of this person is $[(14 - 7)/21]*100 = 33$.

After transformation of scores the level of impairment in one domain compared to that in another can be investigated [3].

Missing values

As scales are constructed in such a way, that items belonging to a scale have high intercorrelation, it is possible to substitute values for missing data. An accepted way of handling missing values in the different (sub)scales of the RSCL is the insertion of the personal scale mean of the respondent on a missing value. This procedure can be followed when the respondent has filled in at least 50% of the items of the (sub)scale in question. In other words, if the scale has an uneven number of items, half the number of items plus one should have been filled in. If fewer items have been completed by the respondent, s/he is considered a missing case for that particular scale.

Alternative options have been suggested recently by Zwinderman (Zwinderman, 1992) and Hopwood and colleagues (Hopwood et al., 1994).

The handling of missing data is still being discussed in the literature. Therefore, it is important that investigators state clearly what they have done when presenting results.

Descriptive use

When the RSCL is used for descriptive purposes, the clinically most relevant information is derived from the percentage of patients who reported being bothered by the symptom to any degree: in other words to dichotomize the results reporting the percent of patients reporting no problems ('not at all') and the percent of patients reporting having been bothered by the symptom (taken 'a little', 'quite a bit' and 'very much' together). Thus an overview of patients being burdened by each symptom is given.

The second option is the integral reporting of levels of distress. If this is needed, the percentage of patients reporting the four levels of symptom distress separately can be given.

Reporting of mean levels of distress regarding specific symptoms and whole scale can only be useful from a clinical point of view if norms are available and, thus, comparisons can be drawn.

Use in treatment comparison

For treatment comparison different results are relevant. Group means and standard deviations can be computed for scale scores and also for individual symptoms. However, most of the scales do not follow a normal distribution and tests based upon medians or non-parametric tests may sometimes be more appropriate. On the basis of these, multivariate testing of group differences and changes over time can be done.

Case detection

The RSCL has been proved useful in the detection of cases and non-cases when establishing psychological or psychiatric morbidity. In those cases a cut off score for the psychological distress scale must be chosen to indicate the presence or absence of 'disease'. Different papers may report different cut off scores based on the sample size and disease status as well as the psychiatric diagnostic criteria used. Most recently a cut off point of 15 was shown to be best in disease-free and stable patients whereas in patients with progressive disease the cut off point yielding good sensitivity and specificity was 16 [4, 5] (Ibbotson et al., 1994).

No cut off scores for physical distress levels or individual physical symptoms are available yet.

2.3 Guidelines for use of the RSCL

Populations

The use of the RSCL has proved appropriate in cancer patients undergoing treatment by different modalities: patients undergoing surgery, chemotherapy as well as radiotherapy. The RSCL has also been used among patients with disease at different sites: breast, prostate, ovarian, lung, colo-rectal, gastric, bladder, renal, head and neck, and testicular cancer as well as heterogeneous groups of cancer patients. The instrument has been used in early as well as advanced disease. Finally, in a number of studies the RSCL has been used in non-cancer or 'normal' populations as comparison groups.

Adaption and modules

It is important to note that no symptoms from the original questionnaire should be left out when using the RSCL. One exception is the item 'go to work' mentioned earlier.

In some studies specific disease- or treatment-related symptoms are relevant to the particular population under study. For example, in patients with distant metastases one might want to study bone pain. Also, in studies where specific treatment side effects are relevant, e.g. hot flushes in hormonal therapy, these may have to be covered. Additional items can be added in the same format as the RSCL symptom distress scale. The selection of extra items should be based on the opinion of experts and patients originating from a population similar to the one to be studied. It is advised that a minimum of three patients and/or experts, mostly clinicians, is approached. Items should be added at the end of the RSCL and not interspersed in the existing scale.

Administration modes

The RSCL may be administered as a self-report questionnaire or by interview. It is readily administered in a clinical setting e.g. in a waiting room, as it has

proved easily understandable it also lends itself to a postal administration.
Telephone interviewing is possible. However, in such situation it is advisable to send a questionnaire to the respondent before the actual interview is done. The respondent then can follow the questions posed over the telephone more easily and can read the questions whilst replying. The same is possible in oral interviewing. If the respondent is given a copy of the questionnaire s/he can read along while the interviewer is posing questions.

'Help' and 'Proxy's'
The RSCL is a self-report questionnaire.
Preferably, the first completion of the questionnaire is assisted so as to ensure that the patient understands the questions. This might be done by a research nurse or a datamanager. If so, it is still essential that the patient fills in the questionnaire him/herself whenever possible.
Sometimes patients ask for advice, for example from partners, when answering the questions posed. This must be avoided as far as possible. It is advisable to make clear instructions in the introduction of the study to prevent this from happening.
Some patients are unable to complete the questionnaire. This may be the result of 'forgetting spectacles', inability to read, cognitive impairment or a severe disease state. Where the patients can not read, the questions have to be read by another person and the patient may still give the answer. In those cases where the patient is unable to answer questions anyway, the questions may be posed to others, 'proxy's'. It is important to note that the answers of these proxy's are bound to be different from the ones patients would have given (Sprangers & Aaronson, 1992). Therefore in those cases where it can be anticipated that the patient will become unable to complete the questionnaire as the disease advances, it is advisable from the outset to ask the proxy as well as the patient each to complete independent assessments thus the original discrepancy may serve as a starting point for understanding bias in later measurements.

Time needed
Patients take, on average, 8 minutes to complete the RSCL.

Use for case detection
The RSCL has proved useful in the detection of psychological or psychiatric morbidity (Hopwood et al., 1991; Ibbotson et al., 1994). This enables the early selection of patients being at risk for distress over the course of the disease. It may also enable the selection of patients who are likely to benefit from psychological or psychiatric intervention. If the RSCL is used as a first screening instrument, a more extensive psychiatric diagnostic interview may than be carried out to investigate further morbidity (Hopwood et al., 1991; Ibbotson et al., 1994).

Number of measurements and measurement moments
If quality of life is assessed in the context of a clinical study, the minimal requirement is to assess it twice during treatment. Thus it will be possible to discern changes over time.
The specific timing of assessment points depends on when toxicity is expected. One wishes generally to sample occasions when the treatment burden is expected to be the greatest and the times at which toxicity is at a minimum. If long term effects are essential in the evaluation of treatment these should be measured at least once.
In an optimal approach it is important to assess quality of life before the start of treatment, preferably before the randomization result is known. At this point patients will not have been informed as to which treatment will be allocated to them. Baseline measurement can help in comparing treatment arms and thus reveal possible differences at the start of treatment. Controlling for background quality of life in the analysis as well as computing change from baseline becomes possible on the basis of the initial measurement points.
If the RSCL is used in the context of an explanatory study in which quality of life is compared or correlated with other (psychosocial) variables, it can be used in the same way.

If the RSCL is used for the detection of clinical cases, it may be used once at the beginning of treatment to test patients for being at risk for developing psychological morbidity. Evidently, it could also be used at other times during the course of disease and treatment, if considered especially relevant.

[1] The earlier British studies referred to were done with a slightly different version of the RSCL: 1) the questions referred to: "to what extent did you have" instead of "to what extent were you bothered by". 2) In these studies the version referring to a 3-day period was still used. 3) The item loneliness was still included.

[2] Some reseachers have used an alternative approach: assigning scores from 0 (not at all) to 3 (very much). Such approach implies that any deviation from 0 implies quality of life impairment. For reasons of comparability such approach should be mentioned when presenting results.

[3] Some caution is needed here. When items are related more closely, i.e. the scale is more homogeneous, a higher score in one item goes along more evidently with a higher score in another item. As a result, as some scales are more homogeneous than others high levels of impairment can be reached more easily when transformation scores are used. This may make scales less comparable than they seem to be after transformation.

[4] Evidently, authors using a scoring system of 0-3 for the individual items should use a cut off score of 7.

[5] The cut off point here would be 9 for a scoring system counting from 0-3.

3 Structure, reliability and validity

3.1 Description of samples

For a quality of life instrument to be useful in any kind of research its psychometric properties should be substantiated. Several studies have been carried out to establish the psychometric qualities of the RSCL. In the overview given below, first the structure of the symptom distress list is described as to support the construction of scales and subscales, secondly the reliability of the (sub)scales is described, thirdly the validity of the instrument is discussed.
Over the last years the RSCL has been used in numerous studies in oncology. It would be impractical to report on the data from all these here. We have therefore made a selection of three. The data from these studies will be supplemented with data reported in the literature [6].

The original Dutch validation studies
The RSCL was validated initially in three study samples. The first consisted of a group of female patients visiting an outpatient clinic for either follow up or chemotherapy administration. The patients (n=86, response rate 90%) were asked to fill in the questionnaire whilst waiting in the hospital, and later give it to their oncologist.
The second sample consisted of a group of 56 patients participating in a randomized trial comparing two chemotherapy regimens (Hexacaf and CHAP-5) for the treatment of advanced ovarian cancer. These patients completed the questionnaire in the clinic several times in the course of the trial (mean number completed: 5.3 and 7.5, respectively).
In the third study a heterogeneous group of cancer patients who had either been operated in the past three months or were receiving chemotherapy, and a group of cancer patients who had been without symptoms of the disease for three years or more, were compared with a random sample of the Dutch population. Patients and controls were sent a letter inviting them to participate, a copy of the questionnaire, and a return envelope. The questionnaire was completed and returned by 78% of the patients currently under treatment (n=216), 87% of the disease-free 'patients' (n=192), and 72% of the normal controls (n=201). The patients under treatment had a mean age of 54, the disease free patients of 61, the comparison group of 45. Of the under treatment sample 30.4% was male, 69.6% was female; of the disease free patients 32.8% was male; 67.2% was female, of the comparison population 40.8% was male, 59.2% was female.

The ZEBRA study
In this trial pre-/peri-menopausal patients, aged less than 51 years, with histologically confirmed stage II node positive breast cancer were recruited. The patients originate from 14 different countries and speaking seven different languages. Of the 887 eligible patients, 689 (78%) completed the first quality of life questionnaire, at baseline. Currently, these 802 patients were potentially available for the second measurement. 544 (68%) questionnaires were available for analysis. 519 patients completed both the first and the second questionnaire.
For the cross cultural comparison clusters of language/culture background have been formed. The sample was divided in six subsamples with a minimum number of respondents of 50 on the basis of the countries involved: 1) an Eastern European sample involving Hungary, Czechia and Slovakia (n=152), 2) an English speaking cluster involving Australia, Ireland and the United Kingdom (n=115), 3) the Finnish sample (n=62), 4) the French cluster involving France and Belgium (n=86), 5) the German sample (n=178), and 6) a 'Latin' cluster involving Argentina, Portugal and Spain (n=96).
Multivariate analyses of variance with the quality of life scales as dependent variables, were performed to establish whether indeed the cluster of countries were similar. Significant differences were found within the Latin cluster only. Patients from Spain differed with respect to quality of life from the ones from Argentina and Portugal but only at baseline. The results regarding this cluster have, therefore, to be considered with caution. Because the on-treatment measurement is especially relevant in the context of this manual, the data from the second measurement point are reported here.

The Fatigue study

In the Fatigue study two patient samples were approached. The Dutch sample involved patients in their last week of radiation treatment (n=141). Patients were given a letter inviting them to participate, a copy of the questionnaire and a return envelope. They were asked to fill in the questionnaire within the next three days. The questionnaire was returned by 98 (70%) of these patients.

The Scottish sample involved 134 radiotherapy patients. They were invited to fill in the questionnaire either in the waiting room in the hospital, or at home within 24 hours. 116 patients (87%) returned the questionnaire.

The Dutch sample filled in the Multidimensional Fatigue Inventory (MFI) along with the RSCL. The Scottish patients completed the RSCL, the MFI and the Hospital Anxiety and Depression scale (HADS).

The SORK study

In the SORK project a cancer patient sample as well as a control group were addressed: 400 newly diagnosed cancer patients (gynaecological, colorectal, lung and breast cancer) and 224 'controls' from the general population matched for age, sex and region of origin. Patients were interviewed by trained interviewers, but the RSCL was filled out as a self-report measure. All subjects came from the North of the Netherlands.

Patients were interviewed three, nine and 15 months after diagnosis. Data from the first and third wave are presented here.

3.2 Structure of the RSCL symptom distress scale

When constructing the RSCL, the symptoms selected to be inserted in the symptom distress scale were gathered, as outlined in the Introduction, on the basis of secondary analyses of results from earlier studies and of interviews regarding relevance of the items. Subsequent studies have investigated whether the symptoms selected could be organised into different scales reflecting more specific quality of life domains. These results will now be reported.

Original Dutch validation studies

In the earlier report on the structure of the RSCL three different factor analyses were reported (De Haes et al., 1990). In the first sample, the first factor (explaining 22.7% of the variance) referred to the experience of psychological distress. The highest loading on the second factor (explaining 7.8% of the variance) had sore muscles and pain in the back. These symptoms, as well as headaches, referred to the experience of pain. A number of symptoms was correlated with this factor less directly related to the experience of pain. The third factor (explaining 5.0% of the variance) referred to the experience of gastro-intestinal complaints: vomiting, nausea and lack of appetite loaded highly on this factor. On the fourth factor (explaining 3.9% of the variance) fatigue and lack of energy were important items. The pattern emerging from this analysis is a structure of four factors, more or less unambiguously concerned with relevant elements in the experience of the disease and treatment. The content of the first factor, psychological distress, is the clearest, that of the other factors, i.e. pain, gastro-intestinal complaints, and fatigue, is less distinct.

In the principal component analysis in the third study two factors had an Eigenvalue of 1.0 or higher. These explained 35.5% of the variance. The first factor (explaining 27.4% of the variance) referred evidently to the experience of psychological distress. All items that at face value would be considered psychological were strongly related to this factor. The second factor (explaining 8.1% of the variance) concerns almost all of the physical symptoms in the checklist. A number of symptoms were weakly related to this factor (sore muscles, low back pain, abdominal aches).

The ZEBRA study

In the baseline measurement of the Zebra study, the two factor structure of symptom checklist gave the best interpretable solution. In this factor analysis the 8 symptoms that were originally part of the first factor were so again: anxiety, tension, nervousness, worrying, depression, despairing about the future, irritability and concentration problems. Three other symp-

toms loaded also, although less strongly, on this first factor. All other physical symptoms had higher factor loadings on the second factor. The earlier two factor solution was thus, largely, replicated.
For the second measurement, where patients completed the questionnaire during chemotherapy, the factor structure was not replicated. As a consequence it was decided to do a factor analysis in which the number of factors was set free. On the basis of the plot of eigenvalues a three and a five factor solution were inspected. The five factor solution gave the best interpretable results. These are given in Table 3.

Table 3

Factor loadings on 5-factor (complete case analysis) solution during treatment for total sample (n=474)

	1	2	3	4	5
anxiety	.79	-	-	-	-
tension	.74	.29	-	-	-
worrying	.73	-	-	-	-
nervousness	.72	-	-	-	-
despairing about the future	.69	-	-	-	-
depressed mood	.65	-	-	-	-
irritability	.64	-	-	-	-
decreased sexual interest	.46	-	-	.29	-
lack of energy	.30	.65	-	-	-
tiredness	-	.63	-	-	-
shortness of breath	-	.58	-	-	-
difficulty concentrating	.44	.54	-	-	-
difficulty sleeping	.30	.50	-	-	-
dry mouth	-	.44	-	-	.31
nausea	-	-	.78	-	.29
vomiting	-	-	.74	-	-
lack of appetite	-	.32	.64	-	-
dizziness	.33	-	.44	-	-
diarrhoea	-	.26	.33	-	-
low back pain	-	-	-	.71	-
sore muscles	-	.25	-	.62	-
constipation	-	-	-	.58	.27
abdominal aches	-	-	.33	.52	-
shivering	-	-	-	.43	-
headaches	-	.35	.29	.35	-
loss of hair	-	-	-	-	.65
sore mouth/pain when swallowing	-	.25	-	-	.63
heartburn/belching	-	.28	.30	-	.46
burning/sore eyes	-	-	.34	-	.44
tingling hands or feet	-	-	-	.31	.40

* only factor loadings of .25 or higher are reported.

As can be seen from this Table, the first factor refers to the experience of psychological distress. Of the original scale all psychological distress symptoms were included. Also was decreased sexual interest. Concentration problems loaded on the second factor along with tiredness, lack of energy, difficulty sleeping, shortness of breath and dry mouth. Apart from the latter, these symptoms are clearly related to the fatigue experience. The third factor was constituted by the following symptoms: lack of appetite, nausea, vomiting, dizziness and diarrhoea. Except for dizziness these factors refer to gastro-intestinal dysfunction. The fourth factor is mainly referring to the experience of pain in different parts of the body: sore muscles, low back pain, abdominal aches, constipation and shivering. Finally, the fifth factor seenXd'o include the symptoms most specifically related to chemotherapy: heartburn, tingling, sore mouth and loss of hair. Headaches are equally related to fatigue and the pain experience.

The Fatigue study

The data from the Fatigue study were analyzed for both samples separately. A non forced factor solution yielded, on the basis of the criterion that Eigenvalues exceed 1 9 factors in both samples. These explained 71% in the Scottish and 72% in the Dutch sample. In both samples, again, the first factor clearly referred to the experience of psychological distress. Seven items are included. The first factor explains 28% in the Scottish and 25% in the Dutch sample. The second factor in the Scottish data refers to fatigue (explaining 9% of the variance), the third to gastro-intestinal symptoms (explaining 7% of the variance). The other factors are less clearly interpretable. In the Dutch data the second factor refers to gastro-intestinal symptoms (explaining 10% of the variance) and the third to fatigue (explaining 7.5% of the variance). The seventh factor (explaining 4% of the variance) refers to pain related symptoms. Other factors are less easily interpretable again except for the one containing diarrhoea and constipation (explaining 4% of the variance).

To conclude

The first factor systematically refers to the psychological distress experience. A two factor model yields a physical and psychological scale. We therefore depart in general from the two factor model. More specifically, factors referring to fatigue and gastro-intestinal symptoms are evident in several samples. In the studies reported by Watson and others (Watson et al., 1992) and Paci (Paci, 1992) in the UK and Italy a gastro-intestinal factor also became evident. It is clear that results are dependent on the sample under study and the moment of measurement. In specific studies, factor analyses may yield relevant subscales. On the basis of reliability testing these can be used further within those studies.

3.3 Reliability

Reliability refers to the amount of random error that is involved in the measurement of a given characteristic. One way of establishing reliability is the assessment of the characteristic a second time as to investigate the repeatability of the score obtained. However, this approach assumes that the characteristic measured remains stable between measurements. This, as will be outlined, is not necessarily true for the quality of life of cancer patients.
Another approach, as followed here, is establishing the internal consistency (Cronbach's alpha) of a scale. Internal consistency is considered the basic requirement for reliability by Nunnally (Nunnally, 1978). Internal consistency refers to the fact that different items in a scale cover the same domain of content. It implies that what is being measured is not a random sample of items, but relates to one domain consistently. For group comparison an internal consistency of .70 is considered satisfactory, for screening purposes, i.e. the detection of cases, it must be .90 (Nunnally, 1978).

Table 4

Reliability of RSCL scales in three studies [1]

	physical symptom distress	psychological symptom distress	activity level
original Dutch validation study			
outpatient clinic[2]	-	-	.91
ovarian cancer patient	-	.94	.95
cancer patients and normals	.82	.88	-
Zebra study (at three months)			
Eastern Europe	.80	.89	.83
English	.80	.86	.71
Finland	.82	.90	.65
French	.85	.86	.61
German	.84	.85	.89
Latin	.85	.89	.42
Overall	.83	.87	.80
Fatigue study			
Scottish sample	.83	.90	.86[3]
Dutch sample	.87	.88	.92[3]

1 Internal consistency unless stated otherwise

2 No symptom subscales were identified at this stage

3 Mokken analysis for hierarchical data

As can be seen from Table 4 the reliability of the physical symptom distress subscale is good consistently over the samples involved. Based on the results of the factor analysis in the second sample of the original validation study and the results from the Zebra study specific physical distress subscales were defined. These pertain to fatigue, pain related symptoms, gastro-intestinal symptoms and chemotherapy related symptoms. In the first study the pain, fatigue and gastro-intestinal symptom subscale have adequate reliabilities (.81, .72 and .88 respectively). In the Zebra study the reliabilities of these subscales is less good (.68; .72 and .63 respectively) [7].

Reliability is consistently good for the psychological distress subscale also. In many of the samples studied the reliability is good enough to warrant the use of the instrument for screening purposes.

The scale regarding the activity level has a varying internal consistency. Inspection of the data of the Zebra study reveals that this is weak when the amount of variance on some items is low in a sample. No patients in these samples experience impairment in the lower levels of activity dysfunction, such as self care. Where variance is sufficient, the reliability of the activity subscale is satisfactory to good.

As in fact the activity level scale is built in a hierar-

chical way we finally computed the reliability using the Mokken model in the Fatigue study. This model is used to establish whether a hierarchical approach would fit the data. The analysis is used to establish whether indeed the items can be seen as a scale where the level of function in one item predicts the level of function in another although the latter may be systematically higher or lower. Violations of the assumption of hierarchy are given in the analysis. For the Dutch as well as the Scottish data the hierarchical structure of the activity level scale was confirmed. No major violations were found. The reliability of the scale was good for both samples [8].
The hierarchical order of the activity scale items was equivalent in both samples:

1 walk about the house
2 care for myself (wash etc.)
3 walk out of doors
4 climb stairs
5 light housework/household jobs
6 go shopping
7 heavy housework/household jobs
8 go to work

To conclude
It can be concluded that the reliability of the physical distress scale is good. The reliability of the psychological distress scale is good and excellent in a number of samples. The use of that scale as a screening instrument is therefore acceptable. The activity level scale has a good reliability in most studies: the internal consistency as well as the hierarchical structure was proven good to excellent. In some samples, as a result of a lack of variance in the samples involved, reliability could not be established.

3.4 Validity

For an instrument to be considered valid it must be established whether indeed it is measuring what it is supposed to measure. The main data available from the studies mentioned and from the literature reported are given in the next overview.

Construct validity
Whether an instrument is measuring what it is supposed to measure can be established in different ways. To established construct validity hypotheses formulated on theoretical grounds are tested. The scores obtained with the instrument have to behave in a predicted manner to support its validity. In this paragraph predictions are based on the fact that the RSCL scale is supposed to be related with criteria 1) measuring the same construct, 2) measuring a related construct or 3) measuring an attribute that is known to be related to the scale [9].

Physical symptom distress was related to the Medical Outcome Study instrument (MOS-20) that measures the patient health state generically (Stewart et al., 1988) [10]. The results are given in Table 5. Physical symptom distress turned to correlate strongly to physical and role function and health perception (all r's >.60). It is related less strongly to mental health. It is unrelated to a one item pain scale.

As on the scale level on the individual item level relations can be studied. In the Fatigue study scores on the tiredness item discriminated significantly between patients scoring high and low on the Multidimensional Fatigue Inventory (MFI).

The psychological distress scale has been related to several other instruments assessing psychological distress or morbidity. Watson and others (Watson et al., 1992) found the psychological distress scale to be highly related with anxiety (r=.74) as well as depression (r=.52) as measured with the HADS. The scale was also related to the Psychosocial Adjustment to Illness Scale (r=.59). Similarly, Paci (Paci, 1992) correlated the RSCL psychological distress scale to Spielberger's Stait Trait Anxiety scale (STAI) and found a strong relationship (r=.74). In the Scottish sample of the Fatigue Study the correlation between the RSCL psychological distress scale and the HADS was .84 for anxiety and .61 for depression. In a Dutch sample from the normal population (n=255) the relation with the CESD-D depression score was

Table 5

Spearman rank correlations between Rotterdam Symptom Checklist (RSCL) and Medical Outcome Study Short Form (MOS SF-20) (n=60)

	RSCL	
	Physical Symptom	Psychological Symptom
MOS SF-20		
Physical Function	-.67 **	-.40 **
Role Function	-.61 **	-.37 *
Social Function	-.58 **	-.33 *
Mental Health	-.53 **	-.78 **
Health Perception	-.62 **	-.60 **
Pain	.09	.16

1-tailed significance * .01; ** .001.

.57, in a sample of cancer patients (i.e. the SORK-study) it was .70 (Bouma et al., 1995). In testicular cancer papients the relation with the MOS-SF20 mental health scale was -.78 (see Table 5) (Kiebert, 1995). In one of the original Dutch validation studies the RSCL psychological distress scale was related to personality characteristics (De Haes, 1988). The scale scores turned out to be strongly correlated with neuroticism (r=.70) and self esteem (r=.63) in disease free patients as well as cancer patients after treatment (r=.67 and -.47 respectively).

The activity level scale has turned out to be related to age as expected in a sample from the original Dutch validation study. In the Fatigue study the activity level scale was related to fatigue subscales as expected: in the Scottish data the correlation with the physical fatigue subscales was .42, .44 and .43. As expected the correlation between activity level and the motivational and cognitive subscales of the MFI was weaker (r=.37 and r=.19).

The item concerning overall evaluation of quality of life ('How was your quality of life over the past week?') has proven, as expected, to be related to individual domains in the quality of life of cancer patients under treatment, notably the evaluation of physical function (r=.75 and r=.79), the evaluation of psychological function (r=.65 and .56), the evaluation of activities (r=.58) and the evaluation of social function (r=.26). Similarly, the overall valuation of life question proved to be related to individual domains in the quality of life of disease free cancer patients: the evaluation of physical function (r=.78), the evaluation of psychological function (r=.67), the evaluation of activities (r=.67) and the evaluation of social function (r=.35). As in the general population it was related to personality characteristics as well. In patients under treatment neuroticism correlated with overall valuation of life (r=.-.20 and r=-.24) as well as self esteem (r=.25 and r=.38). The same was true in disease free cancer patients (r=-.40 and .52 respectively) (De Haes, 1988).

Clinical validity

An instrument meant to measure the quality of life of patients must not only have construct validity, but must also be able to distinguish between clinical characteristics of patients and reflect change in situations which influence their quality of life [11]. In this paragraph clinical validity or responsiveness is substantiated for the different RSCL scales.

The physical symptom distress as measured with the RSCL has been found to be responsive to clinical characteristics. In the first original Dutch validation study chemotherapy patients receiving cisplatinum turned out to experience more gastro-intestinal symptoms as well as hair loss as expected. In the second Dutch study reported on here, the physical symptom distress level was higher in patients receiving chemotherapy and in patients being operated upon for a malignancy compared to the general population and was worse for patients with a poorer prognosis. Patients undergoing chemotherapy reported more physical symptom distress than surgically treated patients and among surgically treated patients physical symptom distress varied with time since the operation (De Haes, 1988).
In the Zebra study patients were experiencing a higher level of physical symptom distress when they underwent adjuvant chemotherapy in all seven cultural groups distinguished.
The Fatigue study can not be used to establish clinical validity as no clinical features were distinguished.
In other studies reported in the literature the clinical validity of the RSCL physical symptom distress measurement has been substantiated. Watson and others (Watson et al., 1992) found the scale to be sensitive to the impact of chemotherapy: patients with disease on chemotherapy had significantly higher mean scores for physical distress scale compared to the disease free group. This difference was greatest for the scale containing gastro-intestinal symptoms. Soukop and colleagues (Soukop et al., 1992) found vomiting to be less prevalent, as expected, in patients receiving anti-emetic treatment. Among patients receiving palliative chemotherapy Richards and others (Richards et al., 1992) found cancer-related symptoms, such as pain and breathlessness, decreased over the course of treatment while treatment-related symptoms, such as vomiting and diarrhoea, increased at 6 weeks and reverted to pretreatment levels after completion of chemotherapy.

The psychological distress subscale has in the first place, as reported earlier, proved sensitive to clinical morbidity as assessed by psychiatric interview in two studies (Hopwood et al., 1991; Ibbotson et al., 1994). Secondly, the scale was related to clinical events as expected in a number of studies. In the original Dutch validation studies psychological distress level has proved to be negatively related to a worse prognosis, receiving chemotherapy, and the expected amount burden of the chemotherapy regimen.
In the Zebra study as in the study by Jones and Coleman (Jones & Coleman, 1993) the level of psychological distress was lower after the initiation of hormonal or chemo-therapy. In the Jones and Coleman study the patients level of psychological distress, interestingly, deteriorated over the second chemotherapy cycle. Soukop and others (Soukop et al., 1992) found patients who received anti-emetic to experience less psychological distress. Richards and co-authors (Richards et al., 1992) found the psychological distress scale to differentiate between patients who received chemotherapy every 3 weeks and those who were treated weekly.

The daily activity scale differentiated between cancer patients. Patients attending their general practitioner and a general population sample in the original Dutch validation study (De Haes, 1983). In the Zebra study, unexpectedly, the activity level of patients turned out to be higher after the initiation of therapy.

The overall valuation of life-scale proved sensitive to a number of clinical parameters in the Dutch validation study. Both surgery and chemotherapy patients reported an impaired overall valuation of life as compared to the general population. Also

patients with the worst prognosis had the lowest quality of life. After surgery the overall valuation of life was worse one month after surgery, when there where clinical problems (e.g. infections) post-surgery. Chemotherapy patients reported a worse overall valuation when the expected burden of chemotherapy was intermediate.
In the Zebra study the overall valuation of life was not impaired after the initiation of therapy in a systematic way.

To conclude, the clinical validity of the RSCL appears to be satisfactory.
The physical distress scales, subscales and individual physical items differentiate between disease and treatment states as well as moments of treatment process.
The psychological scale differentiates between cases and non-cases. Its relation with disease and treatment states has to be clarified further on theoretical grounds. The activity level scale differentiates where expected. The overall valuation is less sensitive, as expected, but still differentiating.

[6] It may be noted that in the original validation study a 27 item version of the symptom checklist was used. In the Zebra and the fatigue study the now accepted version including 30 symptoms has been used.

[7] It should be noted that reliabilities depend on the population under study (De Haes & Welvaart, 1985). Therefore, the reliability of subscales has to be computed anew for new studies before these scales are used again.

[8] Using this analysis the norms for reliability are: <.40 is meagre, <.50 is moderate, >.50 and <1.0 is strong.

[9] The relations given are Pearson correlation coefficients unless stated otherwise.

[10] These data are derived from a study on the quality of life and valuation in testicular cancer patients (Kiebert, 1995).

[11] A problem in establishing clinical validity is that it is not always sure that indeed the clinical characteristic or situation influences the quality of life as expected. Therefore absence of the finding may either mean that the instrument is not clinically valid or that the hypothesis has be formulated erroneously. As will be seen the relation between especially psychological distress and clinical characteristics is not clear yet.

4 Normative data

To be able to compare new results with outcomes of earlier studies, we present data from the study samples mentioned in Chapter 3 (for description of samples, see par. 3.1). The scores are transformed into a 0 - 100 scale as the number of items, as mentioned earlier, was not the same in the original Dutch validation work. All scales are transformed in such way that the lower score implies better functioning or well-being.

Table 6

	physical symptom distress	psychological distress	activity level	overall valuation
Original Dutch validation studies				
I. Various tumour sites, surgery patients (n = 109)				
mean	17.8	21.6	-	28.2
standard deviation	12.0	21.1	-	80.3
range	0-53.3	0-81.0	-	0-83.3
percentile 25	8.3	4.8	-	33.3
50	16.7	14.3	-	33.3
75	23.3	35.7	-	16.7
II. Various tumour sites receiving chemotherapy (n = 108)				
mean	24.0	25.3	-	30.6
standard deviation	13.3	22.2	-	79.7
range	1.7-61.7	0-100	-	0-83.3
percentile 25	13.3	4.8	-	50.0
50	21.7	23.8	-	33.3
75	32.9	38.1	-	16.7
III. Various tumour sites, disease free > 3 years (n = 193)				
mean	15.6	20.4	-	22.0
standard deviation	12.0	20.1	-	20.6
range	0-56.7	0-85.7	-	0-83.3
percentile 25	6.7	0	-	33.3
50	13.3	14.3	-	16.7
75	23.3	33.3	-	16.7

Table 6

		physical symptom distress	psychological distress	activity level	overall valuation
IV.	*Random sample from general population (n = 201)*				
mean		9.9	17.0	-	21.2
standard deviation		9.0	18.1	-	83.7
range		0-50.0	0-85.7	-	0-66.7
percentile	25	3.3	2.4	-	33.3
	50	6.7	9.5	-	16.7
	75	15.0	23.8	-	16.7
Zebra study					
I.	*Early breast cancer, before adjuvant treatment (n = 653-688)*				
mean		11.8	29.6	14.0	30.9
standard deviation		8.9	20.5	16.0	19.3
range		0-57.6	0-100	0-100	0-100
percentile	25	6.1	15.5	0	16.7
	50	10.6	25.0	12.5	33.3
	75	16.7	37.5	23.8	33.3
II.	*Early breast cancer, receiving adjuvant treatment, hormonal or chemotherapy (n = 478)*				
mean		16.3	25.9	8.6	27.9
standard deviation		11.3	19.1	13.1	18.7
range		0-65.2	0-95.8	0-100	0-100
percentile	25	7.6	12.5	0	16.7
	50	13.6	23	0	16.7
	75	22.7	35.4	12.5	33.3
The Fatigue study					
I.	*Various tumour sites, Dutch sample receiving radiotherapy (n = 98)*				
mean		23.6	23.5	24.6	42.46
standard deviation		15.0	21.4	26.2	22.78
range		1.5-59.4	0-85.7	0-87.5	0-87.5
percentile	25	11.6	4.8	0	16.7
	50	21.7	19.1	20.8	50.0
	75	32.3	38.1	37.5	50.0

Table 6

	physical symptom distress	psychological distress	activity level	overall valuation
II. *Heterogeneous, Scottish sample, receiving radiotherapy (n = 134)*				
mean	19.6	26.4	14.4	29.1
standard deviation	12.9	21.8	19.7	22.0
range	0-49.3	0-100	0-75	0-83.3
percentile 25	8.7	9.5	0	16.7
50	17.4	23.8	8.3	16.7
75	27.5	38.1	25.0	50.0
Medical Research Council Clinical Trial Data				
I. *Lung cancer (n=127). Small cell lung cancer, prior to chemotherapy (MRC LU16)*				
mean	27.5	32.9	47.6	51.4
standard deviation	13.9	26.3	30.5	27.9
range	4.3-62.3	0-100	0-100	0-100
percentile 25	15.9	9.5	20.8	33.3
50	27.5	26.1	45.8	50.0
75	39.1	50.0	75.0	66.7
II. *Bladder cancer (n=157). Advanced disease bladder cancer patients, before treatment (MRC BA09)*				
mean	15.9	21.5	33.7	36.1
standard deviation	11.6	21.1	28.7	23.3
range	0-46.4	0-76.2	0-95.8	0-100
percentile 25	8.7	4.8	0	16.7
50	13.0	14.3	29.2	33.3
75	20.3	33.3	58.3	50.0
III. *Head and neck cancer, prior to radiotherapy (n=274) (MRC CH01)*				
mean	17.5	25.8	11.2	-
standard deviation	11.9	20.2	14.7	-
range	0-59.4	0-100	0-66.7	-
percentile 25	8.7	9.6	0	-
50	15.9	21.4	4.2	-
75	23.2	38.1	16.7	-

Table 6

	physical symptom distress	psychological distress	activity level	overall valuation
The SORK study				
I. Various tumour sites, newly diagnosed cancer patients (3 months after diagnosis) n=400				
mean	14.0	16.3	-	-
standard deviation	10.3	17.7	-	-
range	0-55	0-100	-	-
percentile 25	6.7	0	-	-
50	13.3	9.6	-	-
75	20.0	23.8	-	-
II. Random sample from normal population at T1 (n = 224)				
mean	8.9	12.7	-	-
standard deviation	9.0	16.2	-	-
range	0-65	0-95.2	-	-
percentile 25	3.3	0	-	-
50	6.7	4.8	-	-
75	11.7	19.0	-	-
III. Various tumour sites, newly diagnosed cancer patients (15 months after diagnosis) n=400				
mean	12.8	14.6	-	-
standard deviation	11.8	17.7	-	-
range	0-68.3	0-90.5	-	-
percentile 25	3.3	0	-	-
50	10.0	7.1	-	-
75	20.0	23.8	-	-
IV. Random sample from general population at T3 (n = 224)				
mean	9.6	10.7	-	-
standard deviation	9.5	13.9	-	-
range	0-50	0-66.7	-	-
percentile 25	3.3	0	-	-
50	6.7	4.8	-	-
75	13.3	14.3	-	-

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Permission for use of the RSCL

The questionnaire can be used for scientific research. In case of publications, please refer to the following references:

de Haes JC , van Knippenberg FC , Neijt JP. (1990). Measuring psychological and physical distress in cancer patients: structure and application of the Rotterdam Symptom Checklist. Br J Cancer.; 62 (6): 1034 – 1038 .

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Use of the questionnaire in commercial research or in a diagnostic setting, where the respondent is charged in any way, is not allowed.

Complete inclusion of the questionnaire on a website is only allowed for online responding to the questionnaire, for the purpose of scientific research. A reference to this manual should also be placed on that website.

Appendix A

The Rotterdam Symptom Checklist is available in the following languages:

- Dutch
- English
- German
- Portugese (2 versions)
- French
- Hungarian
- Spanish
- Tjecho-Slovene
- Finnish
- Servic

The current Dutch and English versions are given in Appendix B and C

Appendix B

Rotterdamse Klachtenlijst Vertrouwelijk

Datum van invullen _____ 19 _____

Hieronder vragen wij u in hoeverre u last heeft van een aantal klachten. Het gaat er steeds om hoe u zich de afgelopen week voelde. Wilt u een cirkel zetten om het antwoord dat het meest op u van toepassing is.

Bijvoorbeeld: Had U de afgelopen week last van

hoofdpijn	helemaal niet	een beetje	nogal	heel erg

Had u de afgelopen week last van:

gebrek aan eetlust	helemaal niet	een beetje	nogal	heel erg
prikkelbaarheid	helemaal niet	een beetje	nogal	heel erg
moeheid	helemaal niet	een beetje	nogal	heel erg
piekeren	helemaal niet	een beetje	nogal	heel erg
pijnlijke spieren	helemaal niet	een beetje	nogal	heel erg
neerslachtigheid	helemaal niet	een beetje	nogal	heel erg
futloosheid	helemaal niet	een beetje	nogal	heel erg
pijn onder in de rug	helemaal niet	een beetje	nogal	heel erg
zenuwachtigheid	helemaal niet	een beetje	nogal	heel erg
misselijkheid	helemaal niet	een beetje	nogal	heel erg
wanhopig zijn over de toekomst	helemaal niet	een beetje	nogal	heel erg
slapeloosheid	helemaal niet	een beetje	nogal	heel erg
hoofdpijn	helemaal niet	een beetje	nogal	heel erg
braken	helemaal niet	een beetje	nogal	heel erg
duizeligheid	helemaal niet	een beetje	nogal	heel erg
verminderde sexuele belangstelling	helemaal niet	een beetje	nogal	heel erg
je gespannen voelen	helemaal niet	een beetje	nogal	heel erg
buikpijn	helemaal niet	een beetje	nogal	heel erg
angst	helemaal niet	een beetje	nogal	heel erg
verstopping	helemaal niet	een beetje	nogal	heel erg

diarree	helemaal niet	een beetje	nogal	heel erg
maagzuur/oprispingen	helemaal niet	een beetje	nogal	heel erg
rillerigheid	helemaal niet	een beetje	nogal	heel erg
tintelingen in handen of voeten	helemaal niet	een beetje	nogal	heel erg
je moeilijk kunnen concentreren	helemaal niet	een beetje	nogal	heel erg
mond- of slikpijn	helemaal niet	een beetje	nogal	heel erg
haaruitval	helemaal niet	een beetje	nogal	heel erg
branderige ogen	helemaal niet	een beetje	nogal	heel erg
kortademigheid	helemaal niet	een beetje	nogal	heel erg
een droge mond	helemaal niet	een beetje	nogal	heel erg

Hieronder staat een aantal activiteiten. Het is niet van belang of U deze activiteiten ook werkelijk doet, maar of U ze kunt uitvoeren in Uw huidige lichamelijke toestand. Het is de bedoeling dat U telkens die omschrijving aankruist, die het beste past bij Uw situatie van de afgelopen week.

	kan ik niet meer	kan ik alleen met hulp	kan ik zonder hulp, met moeite	kan ik zonder hulp
mezelf verzorgen (wassen e.d.)	0	0	0	0
lopen binnenshuis	0	0	0	0
licht huishoudelijk werk doen	0	0	0	0
traplopen	0	0	0	0
zwaar huishoudelijk werk of klusjes doen	0	0	0	0
lopen buitenshuis	0	0	0	0
boodschappen doen	0	0	0	0
naar mijn werk gaan	0	0	0	0

Hoe voelde u zich, alles bij elkaar genomen, de afgelopen week?

- 0 heel goed
- 0 goed
- 0 tamelijk goed
- 0 niet goed en niet slecht
- 0 tamelijk slecht
- 0 slecht
- 0 heel slecht

Wilt U nagaan of U alle vragen beantwoord heeft?

Hartelijke dank voor Uw medewerking.

patiëntnummer _____

Appendix C

Rotterdam Symptom Checklist Confidential

date of completion _____ 19 _____

In this questionnaire you will be asked about your symptoms. Would you please, for all symptoms mentioned, indicate to what extent you have been bothered by it, by circling the answer most applicable to you. The questions are related to the past week.

Example: Have you been bothered, during the past week, by

headaches	not at all	a little	quite a bit	very much

Have you, during the past week, been bothered by

lack of appetite	not at all	a little	quite a bit	very much
irritability	not at all	a little	quite a bit	very much
tiredness	not at all	a little	quite a bit	very much
worrying	not at all	a little	quite a bit	very much
sore muscles	not at all	a little	quite a bit	very much
depressed mood	not at all	a little	quite a bit	very much
lack of energy	not at all	a little	quite a bit	very much
low back pain	not at all	a little	quite a bit	very much
nervousness	not at all	a little	quite a bit	very much
nausea	not at all	a little	quite a bit	very much
despairing about the future	not at all	a little	quite a bit	very much
difficulty sleeping	not at all	a little	quite a bit	very much
headaches	not at all	a little	quite a bit	very much
vomiting	not at all	a little	quite a bit	very much
dizziness	not at all	a little	quite a bit	very much
decreased sexual interest	not at all	a little	quite a bit	very much
tension	not at all	a little	quite a bit	very much
abdominal (stomach) aches	not at all	a little	quite a bit	very much
anxiety	not at all	a little	quite a bit	very much
constipation	not at all	a little	quite a bit	very much

diarrhoea	not at all	a little	quite a bit	very much
acid indigestion	not at all	a little	quite a bit	very much
shivering	not at all	a little	quite a bit	very much
tingling hands or feet	not at all	a little	quite a bit	very much
difficulty concentrating	not at all	a little	quite a bit	very much
sore mouth/pain when swallowing	not at all	a little	quite a bit	very much
loss of hair	not at all	a little	quite a bit	very much
burning/sore eyes	not at all	a little	quite a bit	very much
shortness of breath	not at all	a little	quite a bit	very much
dry mouth	not at all	a little	quite a bit	very much

A number of activities is listed below. We do not want to know whether you actually do these, but only whether you are able to perform them presently. Would you please mark the answer that applies most to your condition of the past week.

	unable	only with help	without help, with difficulty	without help
care for myself (wash etc.)	0	0	0	0
walk about the house	0	0	0	0
light housework/household jobs	0	0	0	0
climb stairs	0	0	0	0
heavy housework/household jobs	0	0	0	0
walk out of doors	0	0	0	0
go shopping	0	0	0	0
go to work	0	0	0	0

All things considered, how would you describe your quality of life during the past week?

- 0 excellent
- 0 good
- 0 moderately good
- 0 neither good nor bad
- 0 rather poor
- 0 poor
- 0 extremely poor

Would you please check whether you answered all questions?

Thank you for your help.

patient number _____