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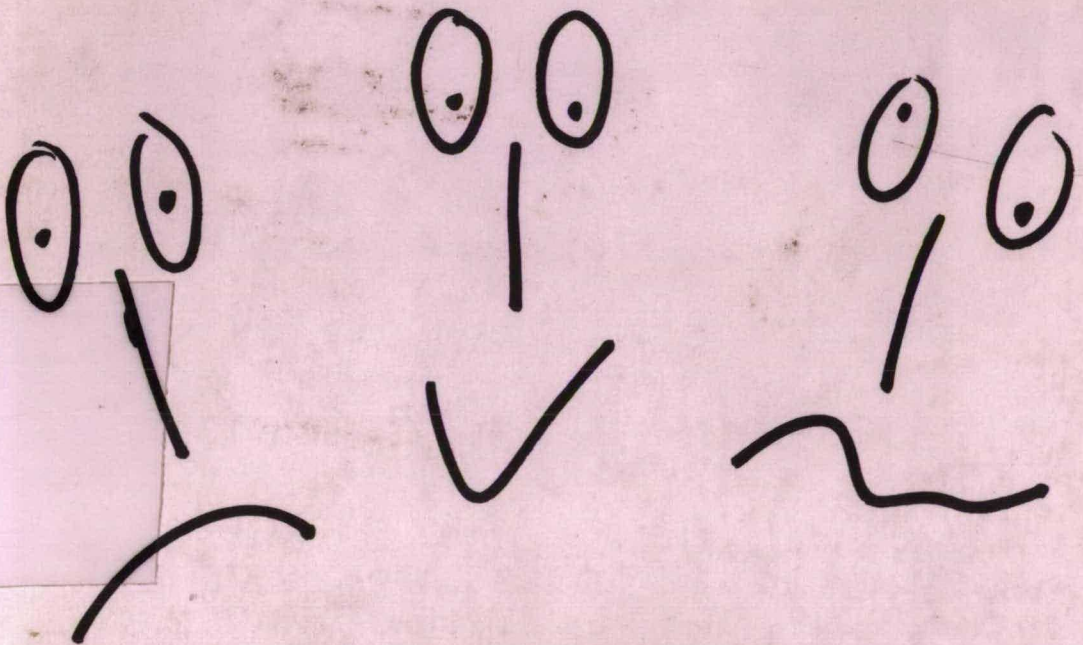
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BEYOND HEALTH STATUS

Construction and Validation of the Dutch WHO Quality of Life
Assessment Instrument

Jolanda de Vries



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**Construction and Validation of the
Dutch WHO Quality of Life Assessment Instrument**

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Construction and Validation of the Dutch WHO Quality of Life Assessment Instrument

PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Katholieke Universiteit Brabant,
op gezag van de rector magnificus,
prof. dr. L.F.W. de Klerk,
in het openbaar te verdedigen
ten overstaan van een door het
college van dekanen aangewezen commissie
in de aula van de Universiteit
op maandag 16 september 1996 om 16.15 uur

door

Jolanda de Vries,

geboren op 3 juli 1967 te 's Gravenhage

Promotor:
Prof. dr. G.L.M. van Heck

Omslag: Paul van den Berg

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Happiness is not
a station you
arrive at, but a
manner of
travelling.

Ogden Nash

to my grandparents



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INTRODUCTION

Nearly all research into quality of life (QoL) is related to health. Health-related QoL is a topic with a continuously growing popularity in health psychology, in spite of the fact that the meaning of the concept is still rather vague. In 1985, De Haes and Van Knippenberg mentioned that health-related QoL has not been defined explicitly. In general, this remark still holds today. One of the few explicit definitions of health-related QoL stems from the work of Patrick and Erickson (1993, p. 20) who have defined health-related QoL as 'the value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy'.

The current popularity of QoL is due to the fact that health-related QoL is increasingly recognized as an important outcome measure and as a supplement to traditional biological end-points such as mortality (Hays & Shapiro, 1992). For instance, information concerning health-related QoL can add to medical knowledge which is obtained in, for instance, the context of clinical trials (Moinpoir *et al.*, 1989).

Although the term that is often used is *health*-related QoL, usually studies focus on *illness* and the impact of illness on health and functional status (Bergner, 1985). In addition, while most authors claim that their instrument assesses health-related QoL, most measures are, strictly speaking, *health status* measures (e.g., Bergner, 1985; Stoker, Dunbar, & Beaumont, 1992) that focus on the influence of the disease on a person's functioning. In most of the health status studies the emphasis is typically placed on the measurement of control of symptoms, which are specific for the disease process (e.g., angina in cardiac disease), physical functional status, and work status (Burckhardt, Woods, Schultz, & Ziebarth, 1989). A lower level of functioning is equated with a lower QoL.

The existing QoL instruments can be divided into groups of *generic*, *disease-specific*, and *domain-specific* questionnaires. Generic instruments are broad measures of health status. They are designed for measuring (multidimensional) QoL in all patient groups, age groups, and sometimes also groups of healthy persons (Fitzpatrick *et al.*, 1992). Two generic instruments that are used very frequently are the Sickness Impact Profile (SIP; Bergner, Bobbit, Carter, & Gilson, 1981) and the SF-36 (Ware, 1993). Disease-specific instruments are measures designed for assessing specific diagnostic groups or patient populations, often with the goal of measuring responsiveness or 'clinically important' changes (Patrick & Deyo, 1989). An example of a disease-specific instrument is the Arthritis Impact Measurement Scales (AIMS; Meenan, Gertman, & Mason, 1980) for rheu-

as physical functioning or psychological health. The Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, and Erbaugh, 1961) is an example of such an instrument.

Because of a number of limitations in the existing QoL instruments, the World Health Organization (WHO) has started a project to develop - cross-culturally - a subjective generic QoL measure called the *World Health Organization Quality of Life assessment instrument* (WHOQOL). The development of this instrument, as well as the study of its psychometric properties, will be the topic of this dissertation.

The first chapter contains an overview of the existing QoL studies and discusses the most prominent QoL measures. In chapter 2, the background of the development of the WHOQOL will be presented. In the following chapters, the two steps that were undertaken to develop the pilot version of the WHOQOL, that is, the employment of preliminary focus groups and final focus groups, will be reviewed. Subsequently, the analysis process that has led to the development of the so-called Field Trial Version of the WHOQOL is described in chapter 5. Studies into the reliability and validity of this Field Trial Version are presented in chapter 6. The last chapter provides the conclusion and future prospects.

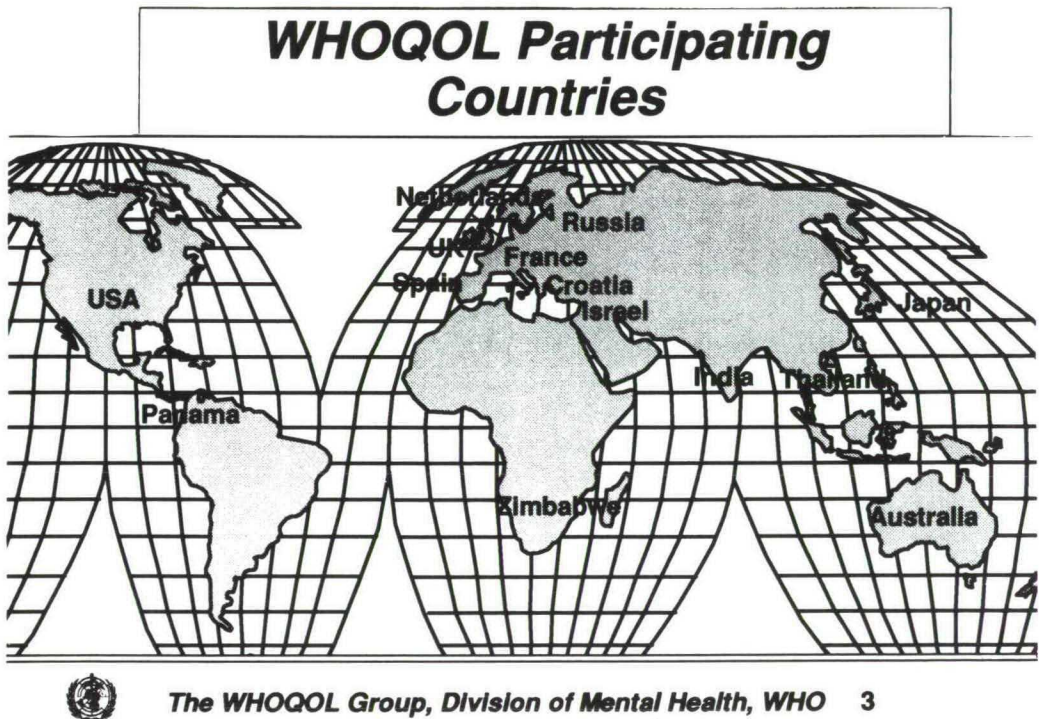
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SAMENVATTING

In 1991 heeft de Wereldgezondheidsorganisatie (WHO) een project gestart, getiteld 'The assessment of QoL in health care'. Het doel van dit project was het cross-cultureel ontwikkelen van een kwaliteit-van-leven instrument dat kwaliteit-van-leven (KVL) in zeer brede zin zou kunnen meten. Dit WHO-instrument diende een uitgebreide meting van algemeen subjectief KVL te omvatten met behulp van globale KVL-vragen.

Dit instrument, genaamd *World Health Organization Quality Of Life assessment instrument* (WHOQOL-100), is een generiek KVL instrument dat zowel bij chronisch zieken gebruikt kan worden, bij mensen die onder stressvolle situaties leven en bij gezonde mensen. De WHOQOL is gelijktijdig in 15 centra verspreid over de hele wereld, ontwikkeld. Deze centra liggen in Australië, Frankrijk, Groot Britannië, (Noord en Zuid) India, Israël, Japan, Kroatië, Nederland, Panama, Rusland, Spanje, Thailand, USA en Zimbabwe (zie Figuur 1).



Figuur 1. De spreiding van de WHOQOL centra over de wereld

Het constructieproces van het instrument bestond uit een aantal stappen. In het aanvangsstadium heeft een expertpanel bestaande uit vertegenwoordigers uit alle 15 centra een werkdefinitie van KVL ontwikkeld alsmede een lijst met facetten (en de bijbehorende definities) van KVL. In deze fase werd KVL gedefinieerd als 'a person's perception of his/her position in life within the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards, and concerns ... a broad-ranging concept incorporating, in a complex way, the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment' (WHOQOL group, 1994a, p. 28). Vervolgens werden er in elk centrum discussiegroepen gehouden. De leden van deze groepen werd gevraagd om te discussiëren over de betekenis van de term KVL. Ze moesten ook bespreken welke facetten bij KVL horen. Nadat de initiële lijst van KVL-facetten was aangepast aan de hand van de opmerkingen van de leden van deze discussiegroepen, werden in elk centrum tenminste zes focusgroepen georganiseerd. De leden van deze groepen waren leken (twee groepen), chronisch zieken (twee groepen) en professionele hulpverleners (twee groepen). In deze focusgroepen stonden de volgende aspecten centraal: de compleetheid van de facettenlijst, de juistheid van de facetdefinities en, vooruitlopend op het samenstellen van een itempool, de wijze waarop naar facetten gevraagd moest worden. Op basis van de transcripties van de gesprekken in de focusgroepen en de WHO-criteria voor het schrijven van vragen, werd de pilot-versie van het instrument ontwikkeld en getest (WHOQOL group 1994a, 1995a).

De pilot-versie van de WHOQOL werd in elk van de 15 centra ingevuld door minstens 250 zieken en 50 gezonde personen. Het doel van de daaropvolgende analyses was om de inhoudvaliditeit van de WHOQOL-domeinen en -facetten te onderzoeken, de beste vragen te selecteren voor elk facet en de interne consistentie en het discriminerend vermogen van de WHOQOL te bekijken (WHOQOL group, 1995a). Naar aanleiding van deze analyses werd de zogenaamde WHOQOL-100 of WHOQOL Field Trial Form (WHOQOL group 1995b; Nederlandse versie door De Vries & Van Heck, 1995) ontwikkeld.

Met behulp van de WHOQOL-100 zijn tot nu toe in Nederland zes validatiestudies uitgevoerd bij verschillende populaties: mensen die lijden aan het Chronisch VermoeidheidsSyndroom, Reumatoïde Arthritis-patiënten, ouderen, gezonden, psoriasis-patiënten en longpatiënten. Hierbij werden de respondenten op diverse manieren geworven, namelijk via ziekenhuizen, patiëntenorganisaties en telefonische recluitering. Uit deze onderzoeken bleek dat de Nederlandse WHOQOL-100 een goede betrouwbaarheid en validiteit heeft. Zowel de interne consistentie als de test-hertest betrouwbaarheid waren ruim voldoende. Tot nu toe kan ten aanzien van de validiteit hetzelfde gezegd worden met betrekking tot de inhoud-, construct-, criterium- en discriminant-validiteit van

het instrument.

Aan het slot van deze dissertatie worden enige toekomstige ontwikkelingen geschetst. Medio 1996 zullen er diverse verkorte versies van de vragenlijst zijn ontwikkeld. Bovendien komen er nieuwe centra die ook een WHOQOL-instrument zullen ontwikkelen volgens een proces dat analoog is aan het proces dat door de 15 kerncentra is doorlopen. Tenslotte zal er onderzocht worden op welke terreinen er behoefte bestaat aan zogenaamde 'aanklik-modules'. Dit zijn series vragen die aan de WHOQOL-100 worden toegevoegd voor een bepaalde populatie (bijv. terminale kankerpatiënten).

Referenties

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Chapter 1 Quality of life: State of the art

The notion of measuring the quality of life could include the measurement of practically anything of interest to anybody. And, no doubt, everybody could find arguments supporting the selection of whichever set of indicators happened to be his choice. (Andrews & Withey, 1976, p. 6).

Everyone has his own set of favored criteria in defining, and consequently his own method in evaluating the quality of life. (Liu, 1974, p. 188).

This chapter is concerned with the history of quality of life (QoL), the conceptualization of QoL, and research findings in the field of health-related QoL. However, primarily attention will be paid to the instruments that claim to measure QoL. The final section of this chapter is devoted to cross-cultural studies in which existing measures have been translated for use in different cultural settings or new measures have been developed cross-culturally.

1.1 General population studies focusing on QoL

After World War II, there was an increasing attention for other aspects of life besides material affairs. This stimulated research into the detection of indicators that reflect the overall 'health' and well-being of the population (e.g., Campbell, 1981; Liu, 1974). At the beginning, the general population was the subject of QoL research as, for instance, in the studies by Andrews and Withey (1976) and Campbell, Converse, and Rodgers (1976). These studies were the starting point in investigating people's QoL. A short review of the literature on QoL, focussing upon studies with healthy subjects or the general population, will be presented in this paragraph. However, firstly the conceptualization of QoL will be the topic of debate. The reason of this is that, although in the last few decades QoL has been a popular research topic which is reflected in a huge increase in the number of studies (cf. Van Elderen *et al.*, 1994), one still has to admit that researchers attach different meanings to the term.

1.1.1 Definition of QoL

The word quality of life is very popular, not only in science. Recently, a monthly magazine in the Netherlands (Bos, 1991) published an interview with eight publicly known persons in which they were asked "What decides the quality of your life?". All eight respondents gave a different answer. Moreover, what they exactly meant by QoL was not clear at all. The same seems to hold for scientists. QoL has been the subject of many studies, but still the meaning of the term is not

uniform and clear. For example, McCall (1975) defined QoL in terms of the satisfaction of general happiness requirements. Others have used the term without defining it at all. Very often a particular word like *well-being*, *subjective well-being*, *mental or psychological well-being*, *life satisfaction*, *level of functioning*, or *subjective social indicators* (e.g., Bradburn, 1969; Campbell, 1981; Carley, 1981; Cherlin & Reeder, 1975; Costa & McCrae, 1980; Evans, 1994; Grieco & Long, 1984; Horley, Carroll, & Little, 1988; Reich & Zautra, 1981; Thomas & Hughes, 1986) is used as a synonym to QoL.

It looks like everyone working on QoL uses his or her own, usually implicit, definition of QoL. However, there have been a number of attempts at defining the concept. Before World War II, QoL was defined as material well-being, that is, in terms of money. Especially at the very beginning of QoL research, nearly everyone defined it in such a material way. For instance, Harland's (1972, p. 17) definition was "the totality of those goods, services, situations and states-of-affairs which are delineated as constituting the basic nature of human life the essential properties of life which are articulated as being needed or wanted". Burt, Wiley, Minor, and Murray (1978) said that one way of conceiving of QoL in a social context was that individuals derive levels of well-being from their existing consumption of goods within society. Also, Gerson (1976) mentioned that the first resource of QoL is money. He answered the question, "But if money isn't enough, what must we add?", by proposing three additional classes of resources and constraints: namely time, skill, and sentiment.

In 1976, Gerson already addressed the problem of defining and measuring QoL. Two years earlier, Liu (1974) rightfully pointed at the fact that researchers who try to define QoL, are inclined to work independently of each other. To use his own words: "Everyone has his own set of favored criteria in defining, and consequently his own method is evaluating the QoL." (p. 188). For instance, Stark and Goldsbury (1990), in research on mental retardation, first defined QoL as representing general well-being which is synonymous to overall life satisfaction, happiness, contentness, and success. Then, they defined the state of general well-being as a function of one's individual characteristics (e.g., age, sex, education level, health conditions), environmental support (i.e., parents, siblings, friends), objective QoL and subjective QoL. Objective and subjective QoL in turn are operationalized by seven domains (health, living environment, family, social/emotional relationships, education, work, and leisure). The only difference between objective and subjective QoL is that the latter is concerned with the way in which the person *perceives* the domains. Such a distinction between objective and subjective has been made very often, for instance, by Oppong, Ironside, and Kennedy (1988).

Objective approaches to QoL assessment assume that observable and quantifiable indicators such

as the physical environment and income are valid measures of QoL and that there are absolute standards for assessing these variables (e.g., Evans, 1994). However, such indicators can be misleading because the effects of culture, values, attitudes, and ideology are not included. The major problem with objective approaches is that links between objective criteria and QoL experienced by an individual are complex and difficult to predict (Evans, 1994; O'Boyle, 1994).

Over time the position has been taken that QoL must be studied from the perspective of the *individual* (e.g., Calman, 1987; Taylor & Bogdan, 1990). In 1981, Campbell defined well-being from a subjective perspective stating that individuals make judgments on the basis of the quality of their own experience, their feelings of being happy and contented, and their sense of well-being. Many researchers followed this perspective (e.g., Andrews, 1991; Andrews & Inglehart, 1979; Badura & Waltz, 1984; Baltrusch & Waltz, 1987; Goode, 1990; Horley *et al.*, 1988; Karan, Lambour, & Greenspan, 1990). For instance, Badura and Waltz (1984) defined QoL as the way the individual feels and Sartorius (1987) defined it in terms of the distance between a person's position and his or her goals. In addition, Andrews (1991, p. 2) defined QoL as "how individuals themselves evaluate their lives".

Reich and Zautra (1981) argued that psychological QoL consists of two separate components: a *positive* component and a *negative* component. This division was originally made by Bradburn (1969) who, in the process of developing the Affective Balance Scale (ABS), found that positive and negative affect were uncorrelated. Gerson (1976) made another distinction: *individual* versus *transcendental* approaches. In the individual approach, the emphasis is on the person's control over his or her circumstances (especially the ability to overcome adversity), freedom from constraint, and similar ideas. In the transcendental approach, the emphasis is on the degree to which a person carries out his/her place in the larger social order. Patterns of both approaches in multiple settings are at the heart of any conception of QoL.

Powers and Goode (in Goode, 1990), asserted that "quality of life is primarily a product of relationships between people in each life setting." (p. 43). Thus, from the above it emerged that subjective QoL can be divided into a *social* and a *psychological* component. In other studies, the concept was divided in different ways. For instance, Liu (1974) defined QoL as the output of two aggregate input factors: *physical* and *spiritual*. Another example can be found in Andrews and Withey (1976, p. 12) who have stated that "quality of life is not just a matter of the conditions of one's physical, interpersonal and social setting but also a matter of how these are judged and evaluated by oneself and others". The values that persons bring to bear on life are in themselves determinants of their assessed quality of life, according to Andrews and Withey. Schallock (1990) indicated that social indicators alone are insufficient to measure individual's perceived QoL and

that it should be measured together with psychological indicators, that focus on a person's subjective reactions to life experiences. In a survey, Krupinski (1980) combined objective and subjective indicators. Burt and colleagues (1978) used objective, social, as well as psychological indicators. Finally, according to Aaronson *et al.* (1991), QoL can be defined most typically in terms of physical, psychological, and social functioning.

In social indicators research no distinction has been made between either social or psychological aspects. In this view QoL encompasses all circumstances of life (Bowling, 1995). In 1988, De Haes, based on the national and international literature, defined QoL as "the subjective judgment of the good and satisfying nature of life as a whole" (p. 7). Recently, Hörnquist, Hansson, Åkerlind, and Larsson (1992) defined QoL in terms of perceived well-being and life satisfaction, globally as well as within key domains. Revicki, Turner, Brown, and Martindale (1992) just equated general well-being with health perceptions and life satisfaction.

1.1.2 Research on QoL

After the Second World War it was realized that people's QoL was not necessarily related only to material wealth. This idea instigated a number of studies in the 1970s. In that period, there was a growing attention to the social, economic, political, and environmental health of nations (e.g., Campbell, 1981; Liu, 1974).

Gurin, Veroff, and Feld (1960) did the first national cross-sectional study about subjective well-being among Americans in 1957. In this epidemiological study, they asked 2,460 persons of 21 years of age or older to describe their feelings of happiness, worries, experiences at work, and experiences with their marriage. When the respondents were asked about the major sources of their happiness, the five sources people mentioned most frequently were economic and material aspects (29%), children (29%), marriage (17%), other interpersonal sources (16%), and job characteristics (14%). At the other end, that is, major sources of unhappiness, economic and material aspects (27%), the statement "not happy about anything" (18%), personal characteristics (13%), community, national, and world problems (13%), and job problems (11%) were mentioned most frequently. It appeared that demographic aspects played an important role in understanding a person's orientation to him/herself. For instance, women had a more negative self-image and were also more introspective. Men stressed their shortcomings in external achievements, while women emphasized personality and interpersonal weaknesses and strengths. In addition, older persons reported more positive self-images. They also expressed fewer problems and fewer feelings of inadequacy. In marriage, as in other areas that were examined, aging appeared to coincide with quality of adaptation, acceptance, and minimization of stress. Both unhappiness and

feelings of inadequacy in marriage were related to experiencing problems in marriage. Furthermore, women expressed more intense feelings of unhappiness in marriage. It was also more likely that they blamed their husbands than the other way around.

In 1969, Bradburn published a study that focussed on the relationship between individuals' life situation and their psychological reactions to that situation. In this study, the emphasis was on positive and negative affect. No significant sex differences with respect to happiness were found. Concerning age, it emerged that the youngest age group was somewhat more likely to report that they were "very happy", whereas persons between the ages of 50 and 59 reported more often to be "not too happy". With regard to race, a number of issues emerged. First, blacks, compared to whites and regardless of educational level, reported twice or three times more often that they felt "not too happy". Second, only at the lower income level there were more blacks than whites indicating that they were "not too happy". The results further showed that persons with a high income and a high level of education, or young and well-educated individuals with the potentiality for a high income, also had the advantage of a positive sense of psychological well-being. Concerning debt, there appeared to be a significant association between worry about debt and psychological well-being. This was true for all income groups except for the highest income group. Furthermore, it appeared that severe income deprivation had a strong relationship to happiness. In addition, physical illness was slightly associated with negative affect. However, it appeared that negative affect was much stronger related to physical symptoms and anxiety. Furthermore, it was demonstrated that sociability was positively related to positive affect. Moreover, there was a positive correlation between quantity of social interaction and positive affect. Concerning marriage, it appeared that persons who were married were much more likely than people who were not married to report that they were "very happy" and positive about their psychological well-being, and much less likely to report that they were "not too happy". When looking only at the persons who were not married at the time of the study, it emerged that the respondents who had been married but were now separated, divorced, or widowed, were by far the unhappiest persons. Comparing men and women in relation to marital status, the findings showed that men who were not married tended to suffer more in terms of avowed happiness and being high in negative affect than women. In addition, single men under 25 were less likely to report that they were very happy than single women under 25, although both were still less likely to be very happy than married people of similar age. Younger single men also had a higher probability of negative affect compared with younger married men. On the whole, there were no marked differences in reports of marriage happiness between men and women and among SES groups. Finally, there was a very strong relationship between the two indicators of happiness [overall & marriage] for both men and

women and at all levels of SES. Looking at employment status, it emerged that unemployment had a negative impact on the happiness of both male and female respondents who were chief wage earners (CWE's) or were married to CWE's. The two effects of unemployment that were mentioned most often were loss of income and a general state of anxiety and worry. Unemployment appeared to be related to both affect dimensions (positive and negative). It could be concluded that for a man the best state was being employed, regardless of the employment status of his wife. In contrast, the best state for a woman appeared to be employed and to have an employed husband. Unemployed men were higher in positive feelings if their wives were employed, while women with an unemployed husband were lower in negative feelings if they had no job themselves. Concerning work there appeared to be a strong and positive association between work satisfaction and overall happiness, irrespective of job status.

The material point of view was never left completely. Because the individual status indicators showed very little explanatory power, Liu (1974) concluded that some minimal economic well-being is a precondition for achieving minimum acceptable QoL. This idea is in line with Maslow's theory that people, when their basic needs are met, will strive for other goals; the highest step in the hierarchy of human needs being self-actualization (Maslow, 1970).

In 1976, two studies were published which are considered as the starting point for the increased attention for QoL. Andrews and Withey (1976) selected five dependent measures to tap two components of psychological well-being: (i) positive states including perceptions of pleasantness of daily life, and (ii) negative states such as distress and depression. Perceived QoL was assessed using the Perceived Quality of Life Scale which was developed for this study. Only a few results will be mentioned here. It was suggested that affective evaluations played a major role in governing the organization of people's perceptions. Andrews and Withey also found support for Bradburn's (1969) finding that positive and negative affect are two independent concepts. Furthermore, the highest relationships with general well-being were found for those aspects that are closely related to people's personal lives such as having fun, enjoyment, self-efficacy, one's marriage, and the extent to which one's physical needs are met. In addition, high-scorers on well-being tended to report positive feelings about their children, spouse and marriage, friends and relatives, and other aspects of one's personal and private world. In general, concerns that had to do with costs of goods and services, taxes, local and national government activities, and phenomena that characterized the national scene in the States were rated at the *Terrible* end of the *Terrible-De-lighted* scale developed by Andrews and Withey (1976).

Subsequently, the respondents were divided into groups on the basis of sex, age, stage in the family life-cycle, socioeconomic status (SES), and race. It appeared that level of general well-

being within all these groups was rather modest. However, with respect to specific concerns, certain groups showed significantly different patterns of positive and negative feelings. For instance, as one advanced in years, feelings about one's health and children became slightly more negative. On the other hand, with advancing years, small increases in satisfaction with domains and values emerged in areas such as home, neighborhood, community, job, government activities and services, and religious fulfillment. These increases counteracted the decreases, consequently showing no significant differences across age groups concerning well-being in general. SES was associated with clear differences in perceived well-being. High-SES was related with being more satisfied, on average, with one's economic status, family, success, health, and job. No differences with respect to SES emerged concerning feelings about neighborhood (except security) or community, interpersonal relationships, and government activities or services. Concerning race, it appeared that blacks reported lower economic satisfactions and some related familial discontents. The same pattern was found among poor people. "Blacks were considerably lower than whites in how they felt about the treatment they receive from other people; they were unusually critical of their neighborhoods and communities, and of local and federal government agencies" (Andrews & Withey, 1976, p. 307). Men and women only differed with respect to worrying. Women reported slightly more frequently than men that they worried. It might be concluded that "most people saw certain flaws in the quality of their lives, and a few (several hundred thousands out of the 140 million adults our samples represent) felt very negative indeed about the level of their well-being" (Andrews & Withey, 1976, p. 334).

Campbell, Converse, and Rodgers (1976) measured QoL by asking their respondents ($N=2146$) about 12 domains: marriage, family life, friends, standard of living, work, community, neighborhood, nation, housing, themselves, health, and education. It appeared that most subjects identified five broad dimensions in which the 12 domains could be placed. These dimensions were (a) physical and material well-being; (b) relations with other people; (c) participation in social, community, and civic activities; (d) personal development and fulfillment; and (e) recreation. The other results of this study will be discussed together with data that were gathered a few years later.

In 1981, Campbell reported on the cross-sectional data that were gathered between 1957 and 1978 by the Institute for Social Research. The 1957 data were already published by Gurin *et al.* (1960) and the data gathered in 1971 were reported by Campbell *et al.* (1976). In the book by Campbell (1981) the results from these two studies were compared with data that were collected in 1978. All three studies were primarily concerned with mental well-being. For it was argued that information about feelings of life can only be learned by asking individual persons themselves. In

these studies the same 12 domains, mentioned above, were included. It was assumed that "an individual's general sense of well-being is determined in large degree by that person's satisfaction with his or her experience in these important domains of life" (Campbell *et al.*, 1976, p. 20). It was further assumed that the importance of a domain could differ over time. However, it appeared that the results were stable over the three measurement points.

The results showed that most married persons judged their marriage as favorable. In addition, they were more positive about their general sense of well-being compared with unmarried persons. It appeared that factors like income, education, occupation, and church preference did not play a role in this judgment. Marriage was more critical to positive feelings of well-being than having children. Most individuals had neighbors whom they knew and socialized with and they also had some relatives living nearby. Furthermore, nearly everyone had at least one friend who was expected to help in times of trouble, whereas five percent of the respondents did not have any close friend or relative. Concerning work, a large majority of the employed individuals indicated that they probably would prefer to continue working even if they would not have to do so for financial reasons. Most men said that they were satisfied with their work. When the 1978 study was compared with an earlier study, there appeared to be no significant changes in level of job satisfaction.

In general, women rated their lives as pleasant and satisfying as men did. Looking at the different data sets, it emerged that the transition for married women from homemakers to working wives was not associated with a corresponding change in reported well-being. Furthermore, it was found that working wives were not happier or more content with their lives than women who still were homemakers. With respect to their community, neighborhoods, and dwelling units, most of the respondents were at least moderately satisfied. There was little change in the public's satisfaction with these environmental aspects during the 1970s. Concerning age, it was shown that young people were not happier than older persons. Although older persons became increasingly dissatisfied with their health during the 1970s, they were, in general, still more content with their lives than younger persons.

Finally, with respect to the self it appeared that persons who had health problems had difficulties accepting this fact. This was especially true for older persons who were least satisfied with their health. Furthermore, persons with serious disabilities (ten percent of the persons in 1971 as well as 1978) had a generally negative pattern of well-being. Overall, for the total population health was not a more powerful contributor to feelings of well-being than other domains. Physical attractiveness was related to high positive affect, being young, healthy, intelligent, well-off, and well-educated. Another predictor of positive feelings of well-being was a strong sense of control

over one's life. This was a more reliable predictor than any of the objective conditions.

Subsequently, smaller studies into QoL and aspects that might be related to QoL emerged. For instance, Brickman, Coates, and Janoff-Bulman (1978) in their study with lottery winners, paraplegic patients, and community controls found that the first two groups were equally happy. Although the patients were unhappier than the controls, they were not as unhappy as the authors had expected.

The relationship between *life events* (even when subjectively reported) and QoL is surprisingly weak, rarely accounting for more than 5 per cent of the variance in current QoL or change in QoL. On the other hand, a number of studies have shown sizeable correlations between various QoL-scales and measures of psychological functioning such as neuroticism, self-esteem, and personal competence (see, e.g., Moum, 1988). Reich and Zautra (1981) asked their subjects to rate major life concerns such as self, family, work, standard of living, leisure, friends, government, and life as a whole on 7-point scales. It appeared that positive origin events led to higher ratings of one's QoL. Furthermore, it was found that certain aspects of life events appeared to be related to satisfaction and distress: (i) positive versus negative affective loading, (ii) location in the past or the present time, and (iii) low versus high perceived control. It was stated that there may be some sort of bidirectional relationship between affective positivity and cognitive control.

Concerning the importance of another category of objective variables, *demographic characteristics* such as sex, age, SES, and marital status, to one's QoL, the reports have not been uniform. Especially in the 1970s, there was a lack of confidence in the relationships between objective indicators and life quality. This was supported by a number of studies (Abbey & Andrews, 1986; Carley, 1981). Schneider (1975) pointed out that the underlying assumption in the field of objective social indicators was that there would be links between objective life situations and subjective feelings of life satisfaction. However, no consistent relationships between objective social conditions of particular cities and perceived well-being of their inhabitants have been found. For instance, Abbey and Andrews (1985; 1986) and Costa and McCrae (1980) found that standard demographic characteristics or social classification variables had practically no relationship with QoL. The usefulness of various classification variables (e.g., sex, race, age, income, and education) for accounting for differences in people's sense of general well-being was also explored by Andrews and Withey (1976). It appeared that none of these variables was able to account for more than 6 percent of the variance of general well-being. Together they accounted for less than 10 percent of the variance. Bryant and Veroff (1982) did not find consistent sex differences across data from 1957 and 1976. In 1988, Moum commented that one of the most replicated findings in QoL research was the very attenuated correlations observed between "objective" indicators and subjective

well-being. Even if one would include the moderately strong association commonly found between marital status and perceived QoL, sociodemographic background variables rarely account for more than 10 percent of the variance in scores obtained with the most commonly employed QoL-scales. On the other hand, in some studies a relationship was found between demographic characteristics and QoL. For instance, Bryant and Veroff (1986) demonstrated divergent validity of dimensions by differentially relating certain demographic measures to various factors. Although men and women did not show major differences in the work of Andrews and Withey (1976), in the Bryant and Veroff study associations with SES, marital status, and race were found. Moreover, Bradburn (1969) found that his Affect Balance Scale showed a pattern of links with social status and income. More recently, Horley and Lavery (1995) reported a positive relationship between subjective well-being and age. It must be noted, however, that this relationship was more straightforward in a cross-sectional design than a longitudinal design.

An implicit assumption of the objective indicators approach is that health and material circumstances, such as the physical environment and the quality of housing, are valid indicators of QoL (Najman & Levine, 1981). In a study by Krupinski (1980), both the objective and the subjective side were incorporated. On the one hand, objective indicators of QoL (social characteristics such as work, income, and housing) were used to determine how people live and a time budget study was carried out to determine how much time people spent weekly on specific activities. On the other hand, the subjective perceptions of the respondents' lives were determined by comparing the importance of specific aspects of life with their actual presence. The following aspects of life were selected for this study: (i) Life in general (family, having no worries, material, personal relationships, doing useful work, recreation, and beliefs and ideas); (ii) Work (independence, dependence, conditions, and freedom from pressure); (iii) School (educational setting, peer activities, closeness to house, and rules); and (iv) Housing (house with garden and flat better than neighbours). It appeared that respondents reported the highest rate of fulfillment of desires on 'family' followed by 'useful work' and 'personal relations'. With regard to work, 'independence' scored the highest proportion of fulfillment. The opposite was true of 'working conditions'. Krupinski also found that the perceived fulfillment of desires had the highest association with health and well-being.

According to Mastekaasa and Kaasa (1988), subjective well-being is most often only weakly related to more objective aspects of people's lives, like living standards, physical health, and social relations. However, in a major review, Veenhoven (1991a) reported that aspects of a basic standard of living such as freedom, democracy, civil rights, basic physical and mental health, and basic level of economic wealth were the only universal discriminators between "happy" and "unhappy" people in 32 countries. In another article, Veenhoven (1991b) reexamined indicators of

(un)happiness such as wealth and handicaps. In general, people are happier when they have better social and personal living conditions. However, the aspect of wealth is subject to the law of diminishing happiness returns. With respect to variables of a subjective or psychological character substantial relationships have often been found with well-being (Mastekaasa & Kaasa, 1988). For instance, De Haes and Van Knippenberg (1985) mentioned that in healthy populations personal functioning, family life and financial position turned out to be the best predictors of sense of well-being.

Finally, Dupont (1980) conducted a study with 39 families with a handicapped child that lived at home. It appeared that the impact on the lives of family members was quite substantial. In the majority of the cases (80%), the parents' sleep was disturbed by the child. Most handicapped children needed constant attention and could not be left alone. Three out of four families had limited cultural activities. Also 75 percent of the families had limited contact with friends and nearly half of the families had restricted contact with relatives. More than half of the families (59 percent) had stopped going on vacation.

In essence, broadening the framework for viewing the spectrum of socio-economic activities by including qualitative, subjective components, (i) by taking this framework to the people for evaluation, (ii) by discovering the outstanding reference points existing, and (iii) finally, by developing and assessing priorities, researchers nowadays are attempting to extend the understanding of what constitutes, conceptually and attitudinally, QoL in a society (*cf.* Harwood, 1976).

In reviewing these studies, no attention was paid to the way in which QoL was assessed. That is why this will be discussed separately in the next paragraph.

1.1.3 Measurement instruments of QoL in healthy persons

Due to the fact that many researchers had their own ideas about what QoL encompassed, in many studies, ad hoc developed questionnaires were used. For instance, Liu (1974) used the following indicators of QoL: status of the individual, individual equality, living conditions, agriculture production, technological development, economic status, education, health and welfare, and state and local governments. One disadvantage of these ad hoc measures is that their reliability and validity is not known. For instance, Campbell (1981) reported that the same set of questions was asked to cross-sections of the inhabitants of the U.S. on three occasions. However, he did not report anything about the reliability or validity of the questionnaires he used. This is true for most of the samples representing the studies in the social indicators field and studies of QoL in healthy persons and general population. This means that it is very difficult to draw definite conclusions from these studies. An exception is the work of Andrews and Withey (1976) who did provide

information about their measures. Andrews and Withey did also various analyses concerning the question that could best be used to assess a person's general feeling about life as a whole. The results suggested that this question was 'How do you feel about your life as a whole?'. Furthermore, they compared different response scales with each other and discovered that their 7-point Terrible-Delighted Scale was slightly better than other response scales such as the ones used by Campbell *et al.* (1976).

A measure of psychological well-being that is still very popular today is published by Bradburn (1969). He developed the Affect Balance Scale (ABS) which consists of two independent dimensions, namely Positive Affect and Negative Affect. The ABS contains ten items, five for each type of affect. The questionnaire appeared to have good test-retest reliability and validity.

As we will see in the next paragraph, in health-related QoL studies the current tendency is a major focus on the development of measures with adequate psychometric qualities. Partly due to this change in QoL research policy, new measures have been developed for assessing QoL in healthy persons. For instance, the McMaster Health Index Questionnaire (MHIQ; Chambers, Sackett, Goldsmith, MacPherson, & McAuley, 1976) has been developed for measuring health in the population at large. It pays attention to the positive aspects of health and assesses relevant changes in health status. For defining health status, the World Health Organization's definition of health (WHO, 1958), which states that health is *not merely the absence of disease or infirmity*, was taken as a conceptual basis (see, e.g., Chambers, 1993; König-Zahn, Furer, & Tax, 1993). The MHIQ has separate scales for physical function (24 items), emotional function (25 items), and social function (25 items). The physical function items cover physical activities, mobility, self-care activities, communication, and global physical function. Self-esteem, attitudes toward personal relationships, thoughts about the future, critical life events, and global emotional function all belong to emotional function. Finally, the social function items cover general well-being, work/social role performance/material welfare, family support/participation, and global social function. The MHIQ is for the most part a health status measure. In addition, it also contains a few subjective items like 'In general, how satisfying do you find the way you're spending your life today?' (Walker & Rosser, 1993). The first validity studies have demonstrated that these self-reports correlate significantly with ratings by external observers. One of the concerns regarding the MHIQ is that it has adequate but not impressive reliability (Chambers, 1993; Kaplan, 1985). Another measure, which will be discussed below (1.2.2.2), is the Schedule for the Evaluation of Individual Quality of Life (SEIQOL; O'Boyle, McGee, Hickey *et al.*, 1993). These two instruments (*viz.* MHIQ and SEIQOL) have also been used in patient populations.

Two instruments that, up to now, only have been used with population samples are the Con-

gruity Life Satisfaction (CLS; Meadow, Mentzer, Rahtz, & Sirgy, 1992) and the Students' Life Satisfaction Scale (SLSS; Huebner, 1991) for elementary school children. The CLS measures subjective well-being with 10 items. The respondents have to answer these items on a 6-point Likert type scale ranging from *Very dissatisfied* to *Very satisfied*. Using this questionnaire, an overall life satisfaction score can be computed. The reliability and construct validity of the instrument seems to be fairly good (Sirgy *et al.*, 1995). The SLSS, which is meant for children of grade 3 and onwards, is a 7-items self-report scale with a 4-point Likert type response scale ranging from *Never* to *Almost always*. It is developed for research purposes. The reliability and validity appears to be good (Huebner, 1995). In addition, it appears that the instrument does not contain racial bias (Huebner, 1995).

The above makes clear that there are not many questionnaires that are constructed for assessing QoL in the general population. Most QoL instruments are developed in the field of health-related QoL. The focus of attention will now turn to this increasingly popular research field.

1.2 Health-related quality of life

Morbidity (illness) might be best assessed through its effects upon QoL. At this moment, most (if not all) studies on QoL are related to health. Usually, although the term used is *health-related* QoL, studies in this area focus on *illness* and the impact it has on health and functional status (Bergner, 1985). In medical research, one is still primarily concerned with medical means for influencing state of health (Tüchler *et al.*, 1992). Bergner (1989) has indicated that all nonmedical outcomes that are considered are thought of as QoL outcomes and labeled as such by clinicians. In line with this, Grieco and Long (1984) see QoL as reflecting impairment in functional performance. In 1982, Kaplan and Bush introduced the term 'wellness' or 'Well-Years' to imply a more direct linkage to health conditions. Three years later, Kaplan (1985) used the term QoL to describe the impact of disease and disability upon daily functioning. Hyland, Finnis, and Irvine (1991) also used a health-related definition of QoL referring to the patient's own subjective interpretation of their life. In another definition of health-related QoL this concept is defined as "the end result of an adaptive process that begins with uncertainty in illness, continues through appraisal of uncertainty as danger or opportunity, and incorporates coping strategies to manipulate the uncertainty in the desired direction" (Padilla, Mishel, & Grant, 1992, p. 156). Finally, Patrick and Erickson (1993, p. 20) defined health-related QoL as "the value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy".

In 1985, De Haes and Van Knippenberg have stated that health-related QoL has never been

defined explicitly. This remark still holds today and some persons actually defend this lack of conceptualization. For instance, according to Van Elderen *et al.* (1994), the way in which QoL is operationalized should depend on the particular perspective of the study. That is, subjective well-being and the expectations of the patients should be the central point of focus, when the perspective of the individual patient is used. In contrast, when QoL is used at an outcome measure at the macro level, the objective functioning of groups of patients on several areas is of a greater interest. Furthermore, Erickson and Scott (1993) have asserted that the approach that people take for assessing QoL depends on two things: the purpose of measurement and the characteristics of the population in focus. According to Schipper *et al.* (1990) QoL is conceived of as the difference between either expectations and the actual performance of a patient or the difference between the actual and potential performance of a patient. The smaller the difference, the better one's QoL.

The emphasis on health-related QoL is due to the fact that it is more and more recognized as an important outcome measure and as a supplement to traditional biological end-points such as mortality (Hays & Shapiro, 1992). Information concerning health-related QoL can add to medical knowledge which is obtained in, for instance, clinical trials (Moinpoir *et al.*, 1989). Van Knippenberg, De Haes, and Trijsburg (1991) have mentioned four factors that contribute to the increase in health-related QoL studies. First, the fact that the population is becoming older and older. Second, the impressive medical technological progress. Third, the growing need for making effects of medical treatment more explicit. Fourth, the need for indicators for well-being of patients including psychological as well as social aspects.

Schipper, Clinch, and Powell (1990) have described a number of approaches which all contributed to the rising of studies on health-related QoL. In each approach another point of view is expressed. For instance, they distinguished between a psychological and a utility approach to QoL. In the former approach, the way in which patients experience their illness and the influence of this experience on the illness process is emphasized. In the latter approach, quantity of life and QoL are weighted against each other. For a long time, quantity of life, that is, keeping people alive as long as possible, was the primary aim in the medical sciences (e.g., De Haes & Van Knippenberg, 1985, p. 809). In that context, mortality and morbidity were the only outcome measures and the primary focus of research (Bergner, 1989). However, medical and biotechnological procedures often reduce the patient's comfort. For instance, "cancer treatment is often intrusive into the patient's physical, emotional, and social life" (De Haes & Van Knippenberg, 1985, p. 809). Living longer may not necessarily mean living better. Evaluating the trade-offs among positive (benefits) and negative (risks) treatment effects becomes more and more important (Mehrez & Gafni, 1990). These trade-offs between length of life and QoL are especially pronounced in

cancer treatments such as chemotherapy (Morrow, Lindke, & Black, 1992). In the 1980s, cancer patients started to indicate that, to them, QoL was often more important (Hunt *et al.*, 1991; Morrow *et al.*, 1992). Then, QoL considerations were added to previous claims which emphasized increased longevity (Najman & Levine, 1981) and from then onwards, health-related QoL started to gain ground and the goals of health care became twofold: it should increase the duration of life *and* improve the QoL (Ware, Brook, Davies, & Lohr, 1981). For instance, Winslow (1992, p. B1) stated that "health care ought to be based and evaluated not just on its impact on mortality rates, but on how patients view its effect on their quality of life". Nowadays, the US Food and Drug Administration approves a new anticancer drug only when it meets the requirement that it is beneficial for the patient's QoL (Morrow *et al.*, 1992).

In health-related QoL research, there is consensus about two fundamental aspects of the QoL concept: *the perspective of the respondent* and *multidimensionality* (Bowling, 1995; Dencker, 1992; O'Boyle, 1994; Ringdal & Ringdal, 1993). Many of the research efforts equate objective disease status with QoL. This confuses morbidity or physiological changes with QoL as subjective satisfaction - the definition being developed by social indicator researchers (e.g., Burckhardt, Woods, Schultz, & Ziebarth, 1989). As stated earlier, the major problem with an objective perspective is that the relationship between objective criteria for QoL and an individual's perspective on his or her QoL is very complex and therefore difficult to predict. So, the use of objective indicators is insufficient to understand adequately QoL experiences. The individual patient must be considered the only person who is able to weight dissatisfactions and satisfactions in a proper way (De Haes & Van Knippenberg, 1985). Objectively, individuals' state of health may be seen as the reflection of poor QoL, because they can no longer do a sizeable number of things. However, in fact, persons may have adapted to that particular situation to such an extent that one has to evaluate the QoL as quite satisfactory (O'Boyle, 1994). That is why the patient's own subjective view and his/her degree of satisfaction are so extremely important.

Moreover, the evaluation of QoL should be health-related and should concern primary QoL domains and major goal areas (Dencker, 1992). Ware and Sherbourne (1992) have stated that there is an increasing consensus regarding the centrality of the patient's point of view in monitoring medical care outcomes. O'Boyle (1994) has presented an example of a person with stage 2 HIV who, objectively (e.g., in terms of housing, mobility, financial security), would have been assessed as having a very low QoL. However, this patient rated his QoL as reasonably good. Therefore, the perspective chosen in studies on health-related QoL is usually subjective, focussing on the patients' *own* evaluation about (aspects of) their QoL (e.g., Najman & Levine, 1981; Ware & Sherbourne, 1992). Thus, the term QoL may be viewed as the expression of a conceptual

model intended to represent the perspective of the patient in quantifiable terms (O'Boyle, 1994). An instrument that uses the person's subjective perceptions and includes the constituent domains of life that are important to persons with chronic illness could provide valuable information for defining areas in which people might benefit from, for instance, nursing strategies geared toward enhancing QoL (Burckhardt *et al.*, 1989). However, operationalization of QoL in the development of QoL measures usually only contains the presence of particular behaviors and feelings. Subsequently, the results are interpreted in terms of experiences of respondents. Rarely measures ask respondents to make their own evaluation of behaviors or feelings. One of the exceptions is the measure used in the study by O'Boyle (1994) mentioned earlier.

QoL consists of a limited number of dimensions. Which indicators are chosen is often based on intuition (De Haes & Van Knippenberg, 1985). Browne *et al.* (1994) reviewed the QoL literature and concluded that there is a low consensus about which domains, criteria, and weights should be used for measuring QoL. They state that "this lack of consensus may be in part explained by the observation that when allowed to nominate the domains of relevance to their life quality, different individuals nominate different domains" (p. 235). However, nearly all measures reflect the multidimensionality of QoL. This is very important because, although a person may be confined to a wheel chair, he or she nevertheless can have a strong psychological well-being or sense of social support. This diversity of experience cannot be captured with a scale that only assess one dimension like the physical dimension (Fitzpatrick *et al.*, 1992). However, the number of dimensions used in most measures is limited (Morrow *et al.*, 1992).

A whole range of aspects influence the choice of the dimensions that one measures in a study. Fletcher *et al.* (1992) have mentioned the following aspects: the severity and nature of a disease, the expected benefits and adverse effects of treatment, considerations such as the length of the study, the availability of suitable instruments, and the environment in which assessment will take place. In spite of these considerations, there are a few domains that are very often included in QoL studies: the *physical*, *mental*, *social*, and *role performance* domains. In addition, especially in clinical trials, often disease-related and treatment-related symptoms are included (e.g., Fitzpatrick *et al.*, 1992; Morrow *et al.*, 1992; O'Boyle, 1994). Schraub, Bransfield, Monpetit, and Fournier (1987) identified the following recurrent themes in the cancer literature: (i) the status of daily physical activities including professional and domestic duties; (ii) the frequency of physical and psychological complaints (e.g., pain, anxiety, depression); (iii) the ability to maintain one's usual sexual functioning; and (iv) the subjective feeling of well-being.

Due to the fact that in many studies QoL is not explicitly defined or defined in different ways, it is difficult to compare the available research findings. In addition, as mentioned earlier, the

operationalization of QoL in terms of questionnaires and their respective questions is realized by asking respondents to indicate whether particular behaviors or feelings are applicable to them. The evaluation of these behaviors or feelings is subsequently done by the researchers and not the respondents themselves. A lower level of functioning is equated by users with a lower QoL.

1.2.1 Research into health-related QoL

Most health-related QoL studies measure *health status*. This implies that the influence of the disease on a person's functioning is assessed. In most of these health status studies the emphasis is typically placed on the measurement of control of those symptoms that are specific for the particular disease process (e.g., angina in cardiac disease), physical functional status, and work status (Burckhardt *et al.*, 1989). An example of a health status statement is 'I isolate myself as much as I can from the rest of the family'. However, studies in which the QoL of patients has been compared with the QoL of healthy persons showed only small differences (De Haes & Van Knippenberg, 1985; Hörnquist *et al.*, 1992). De Haes and Van Knippenberg (1985) have presented a number of reasons for these small differences such as inadequate operationalization of QoL. Flaws, like using measures that are psychometrically unsound and investigating extremely small groups, might also play a role. Another reason for the obtained small differences might be that the individuals' own evaluation of their QoL is not asked. Often respondents can only indicate to what extent they are incapacitated. In addition, only a small range of dimensions are incorporated in the majority of the employed measures. In addition, it might be that ill persons have adapted successfully to their new situation and/or that their norms have changed as a consequence of the new situation.

An aspect that is often not included in health-related QoL studies is *social support*, although this appears to play an important role in person's sense of well-being. For instance, Badura and Waltz (1984) have pointed at socio-emotional and tangible support that children of patients provide as a key factor influencing well-being. In addition, marriage appears to be a major resource in adapting to life with a chronic disease (e.g., Baltrusch & Waltz, 1987; Penninx, Van Eijk, & Deeg, 1995; Van der Zee, Bakker, & Sanderman, 1995). Successful adaptation to life with a chronic illness and perceived health status are major determinants of well-being among the chronically ill (Badura & Waltz, 1984).

A serious illness that is frequently studied is cancer. However, in most cancer studies on health-related QoL the research domain is narrowed to clinical trials (e.g., Fava, 1990). This is not true for studies into other illnesses, where the studies can be divided into descriptive studies, intervention studies, and explanatory studies. Descriptive studies are concerned with describing the

QoL of persons. In intervention studies, QoL is used as a measure to evaluate the effectiveness of a particular intervention such as in clinical trials. Finally, when researchers are trying to find indicators to predict or explain respondents' QoL, these studies are called explanatory studies. It was the intention to provide at least two examples within each of these three types of studies, divided into health status studies and subjective QoL studies. This is shown below.

1.2.1.1 Descriptive studies

Health status studies

In a study by De Witte *et al.* (1989) the Sickness Impact Profile (SIP; Bergner *et al.*, 1981) was used to scrutinize the physical and psychosocial functioning of patients with a rheumatic disease. According to the SIP scores, the most salient problems were in the area of household activities, walking, and recreation/leisure time. The patients were quite positive concerning their physical functioning: 31 percent judged it to be Good or Very good. In addition, the majority (73%) indicated to function psychologically 'good' or 'very good'. However, 18 percent was depressed. Furthermore, nearly half of the patients (47%) tried not to bother their children with illness-related problems. The patients also answered some open-ended questions. The most prevalent negative consequences mentioned by the respondents were pain, fatigue, problems with walking, restrictions in moving, problems with social contacts (loosing friends and acquaintances), being dependent on others, and loosing hobbies. Enjoying life more and changes in social contact ("more depth") were the most prevalent positive consequences of suffering from a rheumatic disease. In research on persons suffering from gastrointestinal disorders, conditions that tend to be chronic and relapsing, it appeared that these disorders affected predominantly sleep, sexual functioning, and employment (McGee, O'Boyle, Hickey, O'Malley, & Joyce, 1991).

In the case of depressed persons it was found that the disease has an enormous effect on a person's social functioning, health status, and well-being (Revicki *et al.*, 1992). In addition, recent evidence from a study with patients suffering from depression disorder or symptoms of depression (Wells *et al.*, 1989) suggested also that these patients tended to have worse physical, social and role functioning, worse health perceptions, and more bodily pain compared to those without chronic medical conditions. In addition, depressed patients demonstrated lower physical and social functioning compared with patients with hypertension, diabetes, arthritis, and gastrointestinal problems (Wells *et al.*, 1989). Winslow (1992) mentioned that in severely depressed persons it appeared that they were physically incapacitated to the same extent as chronically ill persons.

In a study by Burckhardt and others (1989), four groups of patients were asked to fill out three times a number of questionnaires. The respondents suffered from either osteoarthritis, diabetes

mellitus, ostomy secondary to colon cancer or colitis, or rheumatoid arthritis. The questionnaires were the Quality of Life Scale (QOLS; Flanagan, 1978), the Duke-UNC Health Profile (DUHP; Parkerson *et al.*, 1981), and the Life Satisfaction Index (LSI-Z; Wood, Wylie, & Sheafor, 1969). In addition, the Arthritis Impact Measurement Scales (AIMS; Meenan, Gertman, & Mason, 1980) was administered to all patient groups except the ostomy group. The latter respondents answered the Ostomy Adjustment Scale (OAS; Olbrisch, 1983). The interval between the three measurement points was three weeks. The scores at all three measurement points were practically the same. The respondents had an average score of 78 (possible range 15-105) on the QOLS and a mean score of about 45 (possible range 13-65) on the LSI-Z. On the scales of the Duke-UNC Health Profile the average scores were about 0.80 for Symptoms, 0.70 for Social, 0.63 for Physical, and 0.73 for Emotional (possible ranges 0.0-1.0). With respect to the OAS, the ostomy respondents also indicated to be well adjusted to their illness ($M=175$; possible range 34-204). The mean score on the AIMS scales (a high score indicating a more negative impact of illness on a person's life) were as follows: 2.6 for the Physical scale and 2.95 for the Psychological scale. Finally, the average score of the respondents was 5.5 with respect to Pain (possible range 0-10). It can be concluded that, despite their chronic illness, the respondents reported a reasonably good QoL.

Finlay and Coles (1995) made an inquiry among persons suffering from severe psoriasis. Subjects answered questions concerning the history and present status of the illness. Furthermore, the Psoriasis Disability Index (PDI; Finlay & Kelly, 1987) was administered. The overall PDI score reflects the impact of disease over the previous month. Respondents also were posed questions regarding the value that they put on their skin condition. Finally, they were asked to compare their psoriasis with three other diseases: diabetes, asthma, and bronchitis. The results showed that the mean PDI score was 38.8% (range 0-95.6%, $SD=23.3\%$). When the respondents were divided in groups reflecting different sites of their body that were affected, the average PDI score was different for the various groups. A larger difference was obtained, when there was involvement of the hands compared to an involvement of face or feet. Looking at the different questions of the PDI, it appeared that over 50% of the patients responded with either A lot or Very much to the questions relating to clothes, baths, sports, home messiness, and untidiness. Less than 30% responded with these response alternatives to questions concerning career, problems with partner or friends, smoking, and alcohol. Among the respondents there were persons who did and did not suffer from one of the diseases which were used for comparison reasons (*viz.* diabetes, asthma, bronchitis). The majority of patients who did not have these diseases felt that it would be worse to have diseases like diabetes, etc. than to have psoriasis. The mean PDI-scores of those who answered that it would be *better* to have these diseases than to have psoriasis were

higher than the scores of persons who answered that it would be *worse* to have these diseases. In contrast, however, those patients who actually suffered from one of the three comparative diseases, predominantly replied that it would be better to have the comparative disease than psoriasis. Very few thought it would be worse.

Finally, Jacoby (1992) investigated persons with well-controlled epilepsy, that is, persons who did not have a seizure for at least two years. All respondents completed the Nottingham Health Profile (NHP; Hunt, McEwen, & McKenna, 1981), the positive affect items of the Affect Balance Scale (ABS; Bradburn, 1969), the Self-Esteem Scale (SES; Rosenberg, 1965), the Mastery scale (Pearlin & Schooler, 1978), and a Stigma scale (adapted from Hyman, 1971). It appeared that half of the respondents (52%) described epilepsy as "a mild illness". In addition, it emerged that the vast majority (77%) worried only a little or not at all about epilepsy. The majority of the subjects described their health as good or excellent (81%). They did not feel that the illness restricted their social activities (88%). According to these data, epilepsy did not prevent the subjects from doing things (80%). Furthermore, it did not interfere with getting a job, according to 68% of the respondents. When the subjects were divided into four categories ranging from Worrying a lot about epilepsy to Not worrying at all about the disease, the following results emerged. First, a majority of the respondents in each category scored low on the Stigma scale and moderate to high on ABS-Positive Affect. With respect to the NHP, the extent to which persons worried about their illness played a role on three subscales. The more persons worried about their epilepsy, the higher they scored on Energy, Emotional Reaction, and Social Isolation. Also with regard to self-esteem and mastery significant differences emerged. That is, the lesser one worries about the illness, the higher one's sense of self-esteem and mastery.

Subjective QoL studies

In the study by De Witte *et al.* (1989), rheumatic disease patients were asked to indicate on a visual analogue scale how they evaluated their QoL. On average the patients scored 5.3 on a 10 cm-scale. So, it was concluded that QoL was strongly influenced by a rheumatic disease.

Browne *et al.* (1994) did a study among healthy elderly persons and compared them with a sample of younger healthy adults. The elderly filled out the Schedule for the Evaluation of Individual Quality of Life (SEIQOL; O'Boyle *et al.*, 1993), the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), and the Symptoms of Ageing sub-scale of the Self-Evaluation of Life Function Scale (SELF; Linn & Linn, 1985). These questionnaires were answered twice with an interval of one year. They also answered some questions concerning age and sex. With respect to the SEIQOL, it appeared that both times the same five domains of QoL

were mentioned most frequently by the elderly. These domains were family, social and leisure activities, health, living conditions, and religion. In addition, the results showed that at the first measurement point, but not on the second, QoL was significantly higher for the elderly than for a sample of younger healthy adults. In the period between the two measurement points the QoL of the elderly had not changed significant. Furthermore, there was no significant difference in the weights that the older and younger subjects gave to health at time 1 or time 2.

In the study by Burckhardt and colleagues (1989) with four groups of patients, the respondents indicated whether or not QoL had changed during the one year period between the measurement times. Analyses showed that 54% reported that indeed their QoL had changed in the past year. Sixty-three percent of those 54% (34% of the total sample) thought that it had changed for the better. There appeared to be a difference between ostomy patients and other patient groups. Persons with ostomy were much less likely to say that their QoL had changed. However, if it had changed, then they were more likely to say that it had gotten better rather than worse (Burckhardt *et al.*, 1989).

Also another study among elderly persons suffering from chronic diseases, such as arthritis, diabetes mellitus or cancer, showed that QoL tended to be fairly good (Pearlman & Uhlmann, 1988). Here, the elderly as well as their physicians received parallel questions concerning global patient QoL. The responses could range from About as good as it can possibly be (1) to Terrible, quality of life is very bad (6). In addition, the patients had to answer an open-ended question concerning what "events, changes or situations" had improved or reduced their QoL. The patients were also asked to indicate on 4-point scales whether specific potential determinants of QoL such as mood, physical health, psychological well-being, and life satisfaction had affected their QoL in the preceding six months. Finally, the elderly answered questions concerning their health, in comparison with others of the same age and sex, completed the Mini Mental State (MMS; Folstein *et al.*, 1975), and gave information concerning some socio-demographic aspects. These data showed that their QoL was fairly good. In contrast, however, their physicians thought that their QoL was much worse. The patients' perception of their health, interpersonal relationships, and finances correlated high with the patients' rating of their own QoL.

The last descriptive study that will be discussed here was done by Pfeiffer and Wetstone (1988) among 53 patients with systemic lupus erythematosus (SLE). Twenty-five of the patients indicated that they were able to predict flares; nine did not answer the question about predicting flares. The others ($N=19$) reported that they were not able to predict them. The respondents were given both the Positive Affect scale as well as the Negative Affect scale of the ABS (Bradburn, 1969) and a visual analogue scale on which they had to indicate how satisfied they were with their lives. The

total group got average scores of 3.3 (range 0-5) on the Positive Affect scale and 2.6 (range 0-5) on the Negative Affect scale. Their mean Life Satisfaction score was 3.2 (range 1-7). The respondents who indicated that they could predict their flares scored, on average, slightly higher on positive affect and lower on negative affect, but the differences were not significant.

1.2.1.2 Intervention studies

Most intervention studies in which QoL measures were included have been conducted in the field of cancer. Usually these studies are clinical trials to scrutinize the effect on health status of treatments such as chemotherapy and radiation (e.g., De Haes & Van Knippenberg, 1985, 1987; Guyatt, Veldhuyzen Van Zanten, Feeny, & Patrick, 1989).

In 1985, De Haes and Van Knippenberg published an extensive review of the literature on QoL of cancer patients. In this overview they reported the effects of treatment on patients' QoL as found in a large number of studies. They concluded that QoL did not seem to be much effected by treatment. But, more importantly, they pointed at many flaws in the existing studies. Also Guyatt *et al.* (1989) wrote a review article concerning clinical trials with cancer patients. They found that in only 10 out of 55 trials QoL instruments with established validity and responsiveness had been used. Therefore, they concluded that, in spite of the fact that QoL could be measured accurately in randomized trials, it was not widely done. Keeping this in mind, now the results of a number of health status and subjective QoL studies will be reported. It is tried to refer to a wide range of different types of interventions as well as different patient groups.

Health status studies

De Haes, Raatgever, Van der Burg, Hamersma, and Neijt (1987) conducted a study among 56 patients with a histologically verified epithelial ovarian carcinoma in stage III, i.e., advanced stage. The patients were randomly assigned to two different treatments (Hexa-CAF or CHAP-5 regimen) and had to fill in a QoL questionnaire at several measurement points. The questionnaire consisted of the Rotterdam Symptom Checklist (RSCL) which is a list of 34 physical and psychological symptoms (4-point response scale *Not at all - Very much*), a list of eight daily activities such as housekeeping and climbing stairs (4-point response scale *Unable to perform - Able to perform without help*), and a question about one's general impression of physical sense of well-being (5-point response scale *Very well - Very ill*). The results showed that, although it is known that CHAP-5 is more toxic than Hexa-CAF, there did not emerge large differences between the two groups of patients. However, some differences were found with respect to individual complaints. For instance, the patients in the Hexa-CAP group were more irritable and had more

heartburn than the patients in the other group. In addition, they were also more irritable during the treatment weeks. During the first and second courses of treatment (first period) the Hexa-CAP group reported more tiredness and shivering and during the third period (courses 5 and 6) more abdominal aches. On the other hand, the CHAP-5 group experienced a greater lack of appetite and loss of sexual interest as well as a worse sense of well-being compared to the Hexa-CAP group. Furthermore, during the second period (treatment courses 3 and 4) the CHAP-5 group reported more lack of appetite, depression, nausea, vomiting, difficulty concentrating, and diarrhea and more severe gastrointestinal symptoms. In the third period, they again reported more lack of appetite, vomiting, and more gastrointestinal symptoms than the Hexa-CAP group. An inferior sense of physical well-being was also experienced. Finally, the patients receiving CHAP-5 were more distressed by their lack of appetite, loss of sexual interest, and loss of hair during rest periods than the other group.

One hundred and twenty-three CARA patients who were treated multidisciplinary in a intramural health facility in Davos (Switzerland) were studied to establish whether the treatment had any effect on medical consumption and QoL (Van der Schoot *et al.*, 1993). In this study, QoL consisted of three components. Functional aspects were measured with the Daily Activity List (DAL; Schrier, Dekker, Kaptein, & Dijkman, 1990), the Morbidity list (Guyatt, Berman, Townsend, Pugsley, & Chambers, 1987), and the Asthmascore list (Van der Schoot *et al.*, 1993). Psychological aspects of QoL were measured with the Symptom Checklist-90 (SCL-90; Derogatis & Cleary, 1977; Dutch version by Arrindell & Ettema, 1986), the Panic-Fear Symptomatology subscale of the Asthma Symptom Checklist (ASC-pf; Kinsman, Luparello, O'Banion, & Spector, 1973), and a subscale of the Respiratory Illness Opinion Survey (RIOS; Staudenmayer, Kinsman, & Jones, 1978) that measures the extent of stigmatization. Finally, the social aspects of QoL were measured with an adapted version of the Social Support list (Van den Borne & Pruijn, 1983). QoL was assessed 0-4 weeks before admission, 0-4 weeks after discharge, and at 6 and 12 months after discharge. Medical consumption was assessed by asking the general practitioners and lung specialists to provide data concerning the number of visits by the patients and the number of hospital admissions, and the duration of each stay. These data were collected regarding the year before the patient went to Davos and the year following discharge from Davos. The results concerning medical consumption showed that there had been a decrease on all indicators in the year following Davos compared with the year before Davos. With respect to QoL, it appeared that only the functional and psychological aspects of QoL improved. For instance, the DAL scores significantly decreased (which is a favorable change) and the scores on the Depression and Anxiety scales of the SCL-90 also dropped significantly. However, concerning the social aspect of QoL no differen-

ces emerged (Van der Schoot *et al.*, 1993).

Subjective QoL studies

Van Knippenberg *et al.* (1992) reported the results of a study on oesophageal cancer patients. A number of indicators of subjective QoL were filled out before and after a surgical operation in which parts of the oesophagus and the stomach were removed and the digestive tract was reconstructed. The results showed that postoperative, as compared to the pre-test, the global evaluations (the total situation in the previous 3 months and 3 days; prevailing mood and physical well-being during the previous 3 days) remained the same. With respect to the respondents' activity level, psychological distress, and swallowing problems the scores decreased. Finally, the physical symptoms of the patients had increased.

In a study in which the QoL of persons who had received life saving kidney dialysis, renal transplants, or heart transplants were compared, also different aspects of QoL were measured. The objective aspects were functional impairment (Karnofsky Index; Karnofsky & Burchenal, 1949), ability to work ("Are you now able to work for pay full-time, part-time, or not at all?"), and health status (SIP; Bergner *et al.*, 1981). The subjective indicators of QoL were the Index of Psychological Affect, the Index of Overall Life Satisfaction, and the Index of Well-Being; all derived from Campbell *et al.* (1976). Most impaired were the dialysis patients, but on average all three groups had a low mean score¹ (range 1.47-2.88). With respect to ability to work all the groups were impaired. Kidney transplant patients had the highest ability and dialysis patients were the least able to work. The health status of the kidney transplant group was reasonably good (mean 5.52; possible range: 0-100). The other two group had a worse but not terrible health status (means 9.6 and 12.16 for heart transplant and dialysis, respectively). When the subjective indicators were compared, it appeared that the mean scores of all three groups were fairly high on all three measures. In general, the results indicated that the patients who needed dialysis had the worst QoL, objectively as well as subjectively. It could be concluded that a kidney transplant resulted in a higher QoL. This makes sense because dialysis is a disruptive and constant intrusive method of treatment which takes a lot of time. When compared with the QoL of the general population, it was apparent that both healthy and kidney transplant recipients had adapted well to their life circumstances. The results showed that the kidney transplant patients had scored higher than the general population on two out of the three measures of subjective QoL (well-being and life satisfaction). This might be explained by the fact that these patients were survivors. The

¹Possible range 1-10, with 1 meaning 'normal' and 10 meaning moribund.

dialysis patients had reasonably adapted to their disease (Evans, Manninen, Maier, Garrison, & Hart, 1985).

Pruijn and Van den Borne (1987) did a different kind of evaluation research by studying the effectiveness of aftercare by fellow-sufferers. They used structured interviews with two types of cancer patients: Hodgkin's patients ($N=216$) and breast cancer patients with amputation of a breast ($N=282$). All respondents had undergone treatment during the past three years. Among the information gathered extensive questions were asked about social comparisons and contact with fellow-sufferers. It appeared that 109 Hodgkin (51%) and 156 breast cancer patients (55%) indicated to have had contact with one or more fellow-sufferers through the media, face-to-face, or by telephone at some point in time after the diagnosis. For more than half of both patient groups the first personal contact with another patient with the same disease was during the stay in hospital or during first treatment. Concerning the significance that the patients themselves placed on their contact with fellow-sufferers, the following picture emerged. The contact was considered meaningful by half of the persons in both patient groups. A majority of the patients was satisfied with the contacts they had with fellow-sufferers. In the case a patient was not satisfied with this contact, the dissatisfaction was due to negative experiences such as recurrence of the disease, deterioration in health status, or death of the contact person. Furthermore, 34 percent of the Hodgkin's and 17 percent of the breast cancer patients said that they had obtained more knowledge about their disease and treatment through their fellow-sufferer. In addition, half of the patients indicated that through the contact with a fellow-sufferer their self-confidence was at least somewhat confirmed. They also had the idea that they had acquired more control over their situation. Moreover, it had helped them to solve practical problems (38% of the breast cancer patients and 25% of the Hodgkin patients). The contact with a fellow-sufferer had also made them conscious of the fact that other persons with the same disease had the same problems as well as the same feelings of uncertainty and fear. Aspects for which contacts with fellow-sufferers had been particularly important were, for instance, getting a better perspective on one's own situation, feeling understood, and being able to talk about problems and concerns.

1.2.1.3 Explanatory studies

Health status studies

In a sample of 52 recently diagnosed breast cancer patients, Boer, Seydel, Van Rijn, Boekema, and Mak (1992) wanted to test their model of risk factors for psychosocial problems. The scales used were the Karnofsky Index for objective seriousness of the illness, a four-item Subjective Illness Burden scale, and the Dutch Scale for Generalized Personal Effectivity (Boer, Taal, &

Seydel, 1990) for measuring generalized personal effectivity. Furthermore, need for additional medical information and satisfaction with the medical treatment were also assessed, just like age and educational level. The dependent variable, psychosocial problems, was assessed by asking the respondents to indicate in three areas to what extent they had problems due to their illness: symptoms, social problems within the family, and social problems outside the family. Multiple regression analysis showed that three factors contributed significantly to the prediction. Scoring low on generalized personal effectivity was the best predictor of psychosocial problems, followed by higher subjective illness burden and little need for additional medical information. The entire model predicted 60 percent of the variance in psychosocial problems.

Meyerowitz (1983), in a study with postmastectomy patients, hypothesized that denial as a cognitive coping strategy, perceived social support, treatment method, time since operation, and age would account for significant portions of the variance in self-reported QoL. Variables used to measure the QoL of patients were emotional distress, physical symptoms, and dissatisfaction with one's activity level. Emotional distress consisted of depression, anxiety, and hostility and was measured by the Short Form Multiple Affect Adjective Check List (MAACL; Zuckerman & Lubin, 1965). The other measures that were used had been developed by Meyerowitz for this study. Physical symptoms were measured by the Physical Discomfort Inventory (PDI). In this questionnaire the respondents have to rate themselves in three areas: reductions in movements, mastectomy complications, and general physical discomfort. Dissatisfaction with activity level was assessed by the Activities Survey (AS). The Social Environment Scale (SES) was used to measure perceived social support. The SES assesses perceived availability of emotional and social support for five categories of significant others: partner, other family members, doctor/nurse/medical personnel, friends, and other important individuals. Finally, the cognitive (cancer-specific) coping strategy denial consisted of three components. One component, minimization of cancer's impact, was assessed by the Personal Opinion Survey. The two other aspects were the frequency that they thought about each concern in the past month and the level of upset that they experienced when they did think about each concern, measured by a list with health-related as well as general concerns (Hathaway & McKinley, 1943). Using the MAACL, the PDI and the AS, a factor analysis revealed three factors. Two factors, Factor 1 (Distress) containing anxiety, depression, hostility, and physical discomfort and Factor 3 (Dissatisfaction) which consisted of low, moderate and high activity, were used as measures of QoL and entered into a stepwise multiple regression analysis as dependent variables. Results indicated that two cancer-specific denial measures, being upset with cancer concerns and the POS, predicted a significant proportion of the variance in distress. With respect to dissatisfaction, generalized denial proved to be the only significant predic-

tor. It appeared that being low in upset about cancer concerns and minimizing the impact of the disease was associated with the lowest scores on distress, whereas the opposite was related to the highest levels of distress. Higher dissatisfaction was associated with a higher frequency of thinking about general concerns. None of the other variables (treatment group, time since operation, perceived social support, and age) accounted for any significant proportion of the variance in any of the criterion measures.

Subjective QoL studies

In a study on systemic lupus erythematosus (SLE) patients, positive affect, negative affect, and life satisfaction were used as measures of well-being (Pfeiffer & Wetstone, 1988). The impact of the illness was measured by disease duration, symptom perception, dependency, ability to predict flares, pain, and fatigue. Pfeiffer and Wetstone tried to find out which impact measures would predict the respondents' well-being. Therefore, three stepwise regression analyses were executed with positive affect, negative affect, and life satisfaction as the dependent variable. The results showed that the same four significant impact measures (*viz.* dependency, fatigue, ability to predict flares, and disease duration) could be identified for positive affect, negative affect, and life satisfaction. Only the percentages of variance that were explained differed: 28%, 35%, and 22%, respectively.

Extensive interviews with cancer patients suffering from pain revealed that they tend to readjust expectations to fit their current health and functional status in order to maintain perceived QoL at an acceptable level (Padilla *et al.*, 1992).

Pearlman and Uhlmann (1991) reported a study among chronically ill elderly persons in which they wanted to identify independent correlates of global QoL. The dependent variable was a single item asking the respondents to "consider their personal situation and rate their quality of life". Subjective indicators of QoL were attributes and events that could affect QoL. On an extensive list of attributes the respondents had to indicate to what extent each attribute limited their QoL. These attributes appeared to assess seven underlying factors: depression, health, memory, anxiety, finances, residence, and interpersonal relationships. Events were assessed using open-ended questions. In addition, the respondents were administered a list of three questions about their health. Objective indicators were age, gender, educational level, marital status, the Mini Mental State (MMS), number of visits to the physician, number of days that one was admitted to hospital during the last year, and the number of days the respondents had been sick during the last year. Looking at the objective indicators, only the number of visits to the physician and the number of sick days were significantly correlated with global QoL. Concerning the subjective indicators, it

appeared that all seven factors affecting QoL as well as the three health questions were significantly correlated with global QoL. Using linear regression analyses, perceptions of health, memory, and financial concerns, appeared to be the independent correlates of global QoL ($R^2=0.35$). Thus, subjective indicators seemed to be the major determinants of global QoL.

From the studies presented above, it becomes clear that the use of the term QoL is very broad and there are many different instruments for measuring QoL. In addition, most studies are so different from each other, that it is hard to draw general conclusions.

Now that a range of studies have been reviewed in relationship to health-related QoL, the instruments that are used to measure this concept will be discussed.

1.2.2 Measures of health-related QoL

Like there is a wide range in definitions of QoL, there are also many measures to assess it. For instance, Spilker, Molinek, Johnson, Simpson, and Tilson (1990) found 333 QoL measures. However, although most authors claim that their instrument assesses health-related QoL, most measures are just health status measures (e.g., Stoker, Dunbar, & Beaumont, 1992). As Bergner (1985, p. 698) has stated: "Quality-of-life measures used by clinicians and clinical investigators are similar, if not identical, to those I've described as health status indexes or indicators".

The existing instruments can be divided into *generic*, *domain-specific*, and *disease-specific* questionnaires. Generic instruments which measure health-related QoL can usually be referred to as broader multidimensional measures of health status. They are designed to measure QoL in all patient groups, age groups, and sometimes also in healthy persons (Fitzpatrick *et al.*, 1992). They focus on emotional well-being and the ability to function in everyday life (Ware, 1991). In other words, generic instruments purport to be broadly applicable across types and severities of disease, across different medical treatments or health interventions, and across demographic and cultural subgroups (Patrick & Deyo, 1989).

Generic instruments can be used in ways that are not possible with disease- or treatment-specific measures. For instance, generic instruments can be used for comparisons of the relative burden of different diseases and the relative benefits of different treatments (Fletcher *et al.*, 1992; Ware & Sherbourne, 1992). Furthermore, the inclusion of many health-related dimensions removes the need to select dimensions for particular studies and allows for the detection of unexpected effects (Fletcher *et al.*, 1992). On the other hand, there are a number of drawbacks. For example, using generic health measures on a large scale has not been practical because of their length. In addition, they are unable to identify condition-specific aspects of a disease that are relevant for measu-

ring outcome of, for instance, treatment (Bowling, 1995; Ware & Sherbourne, 1992). Finally, such a broad approach to measuring QoL may reduce the responsiveness of an instrument to measure effects of health care (Fletcher *et al.*, 1992).

Disease-specific QoL instruments are developed to measure QoL in specific diagnostic groups or patient populations such as rheumatoid arthritis or cancer, often with the goal of measuring responsiveness or *clinically important* changes (Patrick & Deyo, 1989). Thus, they are developed for one specific disease or a narrow range of diseases such as cancer and focus on problems with these diseases or areas of function (Fitzpatrick *et al.*, 1992; Guyatt *et al.*, 1989). They are especially designed to maximize the detection of clinically significant changes (e.g., Revicki *et al.*, 1992). The development of disease-specific measures has become a major topic in the QoL literature. However, in many cases it has not been established that specific measures give significant incremental information beyond what is provided by a general approach (Kaplan, 1985). This has been demonstrated, for instance, by Kantz *et al.* (1992) in a study with osteoarthritis patients. Disease-specific instruments have several theoretical advantages which are in fact the disadvantages of generic instruments. They reduce patient burden and increase acceptability by including only relevant dimensions. This may increase responsiveness (Fletcher *et al.*, 1992). Patrick and Deyo (1989) also have mentioned sensitivity for the detection and quantification of small changes that are important to clinicians or patients. Disadvantages of disease-specific measures are (i) lack of comparability of results with those from other disease groups and (ii) the possibility of missing effects in dimensions that are not included (Fletcher *et al.*, 1992).

Looking at the pros and cons of both types of measurement, most researchers propose to use both generic instruments *and* disease-specific measures (e.g., Bowling, 1995; Fletcher *et al.*, 1992; Ware, 1991). Generic measures are necessary to compare outcomes across different populations and interventions, particularly for cost-effectiveness studies. Disease-specific measures assess the special states and concerns of diagnostic groups (Patrick & Deyo, 1989). Generic instruments will remain important as long as comparisons across patient groups within and between disciplines are required (Bowling, 1995). In this context, Patrick and Deyo (1989) have stressed the necessity of comparison studies in the same population and in minority and age-specific groups with respect to validity, reliability, and responsiveness of generic and disease-specific measures.

Apart from combining generic and disease-specific measures, Patrick and Deyo (1989) have mentioned that three different strategies are possible: the use of (i) separate generic and specific measures, (ii) modified generic measures, and (iii) disease-specific supplements. The preferred strategy depends on project aims, methodological concerns, and practical constraints. In QoL

assessment, it is often the case that generic measures are tailored for specific disease categories (Kaplan, 1985). These approaches combine the assessment of general function with indicators that are very specific for a particular disease or disability. Another approach is to use generic QoL measures and include some additional items that are relevant for a particular disease process. In any case, a combined approach to QoL assessment, using both disease- (or condition-) specific and generic measures is preferable where a broad disease-specific QoL instrument has not been satisfactorily developed (Bowling, 1995).

Domain-specific measures only assess one QoL domain such as physical functioning or psychological health. These instruments are used when the investigator is only interested in a particular aspect of QoL.

In this section, a number of objective health status and subjective QoL instruments are presented in order to give an indication of the type of measures that are available. Within these two broad types of instruments, the questionnaires that are discussed are divided into generic and disease-specific QoL questionnaires. If possible, the most frequently used questionnaires were described. In addition, the striving was to discuss at least one measure in each category, although this was sometimes rather difficult, partly due to the fact that measures and studies are published in a wide variety of journals across different disciplines.

For a more extensive review of presently available instruments the reader is referred to Bowling (1995) for disease-specific measures and Walker and Rosser (1993) for the more generic type of health status questionnaires. To the author's knowledge, there does not exist such an extensive review concerning subjective QoL measures.

1.2.2.1 Health status instruments

Generic measures of quality of life

Some of the uses of generic health status and QoL measurement include: (i) the measurement of the effects of health care interventions, (ii) the evaluation of the quality of care, (iii) the estimation of the needs of a population, (iv) the improvement of clinical decisions, and (v) the inquiry of the causes and consequences of health status (Ware *et al.*, 1981). Measures of health status were - and still are - based principally on the *negative* aspects of health (Bergner, 1985).

There are numerous generic health status measures, i.e., indexes that examine dysfunction or disability (Bergner, 1985). One of the best known and widely used assessment instruments is the Sickness Impact Profile (SIP; Bergner *et al.*, 1981), developed in the United States. The SIP measures the impact of disease on a patient's life. It is applicable to acute as well as chronic illness and to individuals (using a profile) as well as groups. The original instrument consists of

136 items belonging to 12 categories of which 3 (Ambulation, Mobility, and Body Care and Movement) can be used to constitute a physical dimension. Social Interaction, Alertness Behavior, Emotional Behavior, and Communication can be aggregated to make up a psychosocial dimension. The other categories are Sleep and Rest, Eating, Work, Home Management, and Recreation and Pastimes. Scores on this instrument are transformed into percentages that indicate the impact of the disease on a person's life (Bergner, 1993). The higher one scores on a scale (possible range 0-100), the higher the disease impact. So, the SIP measures dysfunctioning. Healthy people score below 6 on the scales (König-Zahn *et al.*, 1993). Its reliability and validity are good (Bergner, 1993; De Bruin, De Witte, Stevens, & Diederiks, 1992). The SIP has been used in different types of patient group like rheumatoid arthritis, cancer, and psoriasis (König-Zahn *et al.*, 1993). There is now also a short generic version of the SIP available, the SIP68. This version, developed by De Bruin, Diederiks, De Witte, Stevens, and Philipsen (1994), contains 68 items covering the following categories: Somatic Autonomy (17 items), Mobility Control (12 items), Psychic Autonomy and Communication (11 items), Social Behavior (12 items), Emotional Stability (6 items), and Mobility Range (10 items). The reliability and validity of the SIP68 seems to be good (De Bruin, Buys, De Witte, & Diederiks, 1994).

The Nottingham Health Profile (NHP; Hunt, McKenna & McEwen, 1989) consists of two parts. Part I reflects health problems and covers the following six areas: energy, pain, emotional reactions, sleep, social isolation, and physical mobility. This part consists of 38 statements. Each statement has its own weight which was developed using the Thurstone method of paired comparisons. The scores for each of the six areas can range from 0 (*No health problems*) to 100 (*All statements are confirmed*). Part II contains statements relating to areas in life that might be affected by illness. These statements cover paid employment, jobs around the house, social life, family relations, sex life, hobbies/interests, and holidays. The validity of the NHP has been established with a wide range of different groups like firemen, pregnant women, elderly persons, and fracture victims. For establishing the reliability patient groups like osteoarthritis patients and peripheral vascular disease patients were used (McEwen, 1993).

The last generic health status instrument that will be discussed here is the 36-item Medical Outcome Study Short Form/RAND-36 (SF-36; Ware, 1993; Van der Zee & Sanderman, 1993). Although this measure is not a purely objective health status measure, it is discussed here because it best fits this category and considering its popularity, the SF-36 is a measure that must be included. Most items of this measure were derived from different batteries of the Rand Corporation that have been used for 20 to 40 years or longer. It includes one multi-item scale that assesses eight health concepts: (i) limitations in physical activities because of health problems; (ii) limitati-

ons in usual role activities because of physical or emotional problems; (iii) limitations in usual role activities because of physical health problems; (iv) bodily pain; (v) general mental health (psychological distress and well-being); (vi) limitations in usual role activities because of emotional problems; (vii) vitality (energy and fatigue); and (viii) general health perceptions. The testing yields a composite QoL score on a scale of zero to 100. In addition, scores can be calculated for individual ratings in physical, social, and emotional status (Winslow, 1992). The SF-36 can be used as a self-administered questionnaire, but can also be administered by a trained interviewer either in person or by telephone. It is meant for persons aged 14 years and older (Ware & Sherbourne, 1992). The SF-36 is short and sensitive to intervening illness, for instance, among the relatively healthy elderly. This measure appears to have a good reliability and validity (Bowling, 1995). The questionnaire is available in many languages and it is becoming the most preferred generic core instrument in disease-specific batteries.

Besides generic health status measures, there are also instruments that only measure one domain of QoL. An example of such an instrument is the Activities of Daily Living (ADL; Katz & Akpom, 1976a, 1976b). The ADL is most useful in studies of the elderly and those confined to long-term care institutions. It includes scales that describe six functions: bathing, dressing, toileting, transfer, continence, and feeding. For each category, a judgment is made as to whether the person is independent or dependent. ADL has been used in a large number of studies, and its validity and reliability are well established. The major limitation of the ADL Scale is that it does not make distinctions toward the well end of the QoL continuum.

The Karnofsky Performance Index (KPI; Karnofski & Berchenal, 1949) is a simple rating form that requires a physician or another health care professional to assign a percentage score to a patient's physical performance and dependency. Although it was not designed as a QoL measure, it is often used as one. The scores range from 0 (dead) to 100 (normal with no complaints and no evidence of disease). The patient's feelings are not taken into account. It has found widespread use in cancer research (Kaplan, 1985), probably because it has been demonstrated that it is a reasonable predictor of treatment outcome (Bowling, 1995). Among the advantages of the KPI is the fact that it is easy to use and attempts to relate disease or disability to daily functioning.

Disease-specific measures

A number of disease-specific QoL measures will be discussed here: the European Organization for Research on Treatment of Cancer (EORTC; Aaronson *et al.*, 1991), the Arthritis Impact Measurement Scales (AIMS; Meenan *et al.*, 1980), the Health Outcomes Institute TyPE Scales (HOI-TyPE-COPD; Bowling, 1995), the Living with Asthma Questionnaire (LAQ; Hyland, 1991;

Hyland *et al.*, 1991), the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), and the Quality of Life Index (QLI; Bonanno, Gibbs, & Twardzicki, 1982).

The EORTC project used the cancer modular format to develop an instrument, which comprises a core of generic QoL items together with more specific instruments, so-called modules, designed for each of the main types of cancer (Fitzpatrick *et al.*, 1992). The rationale for the construction of the core questionnaire of the EORTC, the Quality of Life Questionnaire-Core 30 (QLQ-C30), was that for an optimal clinical use QoL should be defined and assessed in terms of its component parts (Aaronson *et al.*, 1991). Thus, QoL was defined in relation to the core elements of functional status, cancer and treatment-specific symptoms, psychological distress, social interaction, financial/economic impact, perceived health status, and overall QoL (Bowling, 1995). The EORTC QLQ-C30 is multidimensional, cancer-specific, patient-based, and measures functional status (Moinpour *et al.*, 1989). In addition, it is designed for self-administration and intended for application across a range of cancer diagnoses (Ringdal & Ringdal, 1993). The QLQ-C30 is regarded as the core instrument. This means that it is applicable for most cancer patients. This core instrument can be supplemented by modules that cover items that are specific for a particular type of cancer. At this moment there are three modules available: breast cancer, lung cancer, and oesophagus cancer. The reliability and validity of the QLQ-C30 appears to be reasonably good (Bowling, 1995). However, Ringdal and Ringdal (1993) make objection to the 2-item scales as well as the use of six single items. They suggest to expand the questionnaire in such a way that all dimensions are measured by at least three items.

The AIMS measures the health status of patients suffering from rheumatoid arthritis. The instrument consists of 45 items which constitute seven subscales: Dexterity, Physical Activity, Mobility, Household Activities, Activities of Daily Living, Depression and Anxiety, and Pain. Patients can fill out the AIMS in 15 to 20 minutes. This instrument is used in clinical therapeutic trials and appeared to have a good reliability and validity (Deyo, 1993).

The HOI-TyPE-COPD was designed for repeated application in persons suffering from Chronic Obstructive Pulmonary Disease and consists of a patient form and two forms for clinicians. The patient form contains 22 questions, some of which are multi-item questions (*cf.* Bowling, 1995). The questions cover aspects like smoking, service use, medication, symptoms, and the Physical Functioning subscale of the SF-36. The two clinician forms cover diagnosis, results of tests, and medical history (Bowling, 1995). There also exist a range of HOI-TyPE instruments specific for other diseases such as hypertension and stroke.

The LAQ consists of 68 items covering 12 domains of QoL: social/leisure, sport, holidays, sleep, work and other activities, colds, mobility, effects on others, medication use, sex, and

dysphoric states and attitudes (*cf.* Bowling, 1995). It was developed to evaluate treatment programmes for adults suffering from asthma. Focus group methodology was used to generate the structure and items for the LAQ. Its reliability and validity seem to be good, although further testing is needed (see Bowling, 1995).

The QLI is a survey that has to be filled in by proxies, such as residential service providers. It was designed to measure the ambiance, friendship, and happiness of people with mental retardation. In order to fill in this measure, one has to obtain information from different sources. In this way one has tried to overcome the problem of proxy ratings. The overall purpose of the survey is to improve QoL in day centres and residential centers. The questionnaire seems to be valid and reliable (Borthwick-Duffy, 1990).

A measure that is developed to assess clinical depression is the BDI. This measure is not only disease-specific but also domain-specific because it only contains items in the domain of psychological health. It is a very popular questionnaire which is used in all kinds of studies (e.g., Arasteh, 1994; Dalack, Glassman, Revelli, Covey, & Stetner, 1995; Goodale & Stoner, 1994; Heebink, Sunday, & Halmi, 1995; Kok, Heeren, Hooijer, Dinkgreve, & Rooijmans, 1995). This measure consists of 21 items on cognitive symptoms of depression. The questionnaire covers a wide range of aspects of depression. Some examples are sadness, sense of failure, guilt, and self-dislike (Beck *et al.*, 1961). The time frame is the past week. Completing the BDI takes 10 to 15 minutes. Norms are available. There are two forms: a self-administered and an interviewer-administered form. This measure has good reliability and validity (*cf.* Bowling, 1995).

In the following paragraph, a number of subjective QoL measures, generic as well as disease-specific, will be discussed.

1.2.2.2 Subjective QoL instruments

Generic measures

In contrast to the large number of generic objective measures, the number of generic *subjective* QoL measures is limited. Three questionnaires will be discussed here. The Subjective Well-Being Inventory (SUBI; Sell & Nagpal, 1992), the Schedule for the Evaluation of Individual Quality of Life (SEIQoL; O'Boyle *et al.*, 1993), and the domain-specific Psychological General Well-Being index (PGWB; Dupuy, 1984).

In 1992, the final form of the SUBI has been published. This questionnaire is mainly used in India and Sri Lanka. It measures 11 factors: General Well-Being - Positive Affect, Expectation - Achievement Congruence, Confidence in Coping, Transcendence, Family Group Support, Social Support, Primary Group Concern, Inadequate Mental Mastery, Perceived Ill-Health, Deficiency in

Social Contacts, and General Well-Being - Negative Affect. All factors, except Inadequate Mental Mastery and Perceived Ill-Health, are assessed using three items. Each of the other two factors are measured by six items. This measure is reliable and appears to have a good validity (Sell, 1994).

An individual measure of QoL is the SEIQoL constructed by O'Boyle and colleagues (1993) and developed for healthy adults of all ages, although it can also be used in patient populations. The scale can only be used in those cases where diseases did not impair cognitive functioning or motivational state. For, respondents must have the insight to indicate which factors determine their lives. The procedure goes as follows. First, each respondent is asked to name the five domains that he/she feels are the most salient to his/her QoL. This information is gathered during a semi-structured interview. Subsequently, the respondent is requested to rate his/her current levels of functioning on each of the five selected domains. The rating is given on a vertical scale ranging from 0 to 100. These extremes are anchored with the terms *Best possible* and *Worst possible*. Finally, judgment analysis is used to quantify the relative importance of each of the five domains have for his/her QoL. The SEIQoL appears to have good validity and reliability (Browne *et al.*, 1994; O'Boyle, 1994).

Finally, an instrument that only measures one domain of QoL is the PGWB, also known as the General Well-Being Schedule (GWBS). As the name already suggests, this measure assesses the psychological or emotional domain. This questionnaire consists of 22 items covering six aspects of the psychological domain: depressed mood, anxiety, vitality, general health, positive well-being, and self-control. In addition, a total PWBS score can be obtained. The reliability and validity of this instrument appears to be good (Bowling, 1995; Dupuy, 1984).

Disease-specific measures

Comparable to the case of generic subjective measures, also the number of disease-specific subjective instruments is rather limited. Three such questionnaires will be discussed here: the Client Satisfaction Questionnaire (CSQ; Larsen, Attkisson, Hargreaves, & Nguyen, 1979), the CARDIAC (Faris & Stotts, 1990), and the Diabetes Quality of Life Measure (DQOL; Diabetes Control and Complications Trial Research Group, 1988).

The CSQ was developed to evaluate mental health programmes from the clients' perspective. There are different versions of the CSQ, the longest containing 31 items. The reliability and validity of the CSQ seems to be reasonably good (Bowling, 1995). Although this instrument measures the clients' perspective, the questionnaire was constructed from the perspective of health professionals.

Faris and Stotts (1990) have developed a subjective QoL measure for persons suffering from

percutaneous transluminal coronary angioplasty. It deals with two aspects: satisfaction and importance. Example items are "How satisfied are you with your physical independence (ability to do things for yourself, get around)?" for *satisfaction* and "How important is your physical independence (ability to do things for yourself, get around) to you?" for *importance*. Although the CARDIAC is a reliable and well-known instrument, it has only been used only a few times (Bowling, 1995).

Finally, the DQOL is a measure for insulin-dependent diabetes mellitus patients. This measure consists of 46 core items covering three topics: Satisfaction, Impact, and Worry. The latter is divided into Worry about the disease and social/vocational worrying. "How satisfied are you with the time you spend exercising?" is an example of a Satisfaction item. An illustrative Impact item is "How often do you find that your diabetes interrupts your leisure time activities?". "How often do you worry about whether you will pass out?" is an example of a Worry about Diabetes item. When considered appropriate, 16 questions concerning school and family relationships can be added. The response scales are 5-point Likert type scales. The reliability and validity of the DQOL appears to be good, although some doubt has been casted concerning its value above a generic QoL measure (Bowling, 1995).

One major drawback of most existing health status and QoL instruments is that they are only available in one or two languages. To overcome this, a number of international projects have been started to translate measures into other languages or to develop cross-culturally new measures.

1.3 Cross-cultural measures

In the field of QoL, it is only during the last decennium that attention has been given to cross-cultural studies and the measurement of QoL across cultures. Especially pharmaceutical industries have shown to be very keen on measures that can be used in different countries. Their interest is in international cooperative clinical trials requiring multilingual QoL instruments (Tüchler *et al.*, 1992). One measure that can be used in several countries will make comparisons between results much more straightforward. In addition, the interest in cross-cultural studies is increasing and therefore the eagerness with which universal instruments are sought.

Kuyken, Orley, Hudelson, and Sartorius (1994) mentioned four different approaches that are used in cross-cultural contexts regarding measurement instruments. First, the development of new measures for particular settings, purposes, and populations. This is by far the most common approach. Examples of generic measures that have been developed for one particular culture without thinking of a possible use outside that particular setting are the SIP and the SF-36. Second, an existing measure can be adapted or translated for other settings. For instance, this was

done in the case of the SF-36, the NHP, and the Dartmouth COOP charts. Third, one can set up a collaborative study aiming at the development of an instrument in several (very diverse) cultures. The only two existing projects using such an approach are, to our knowledge, the WHOQOL project, which will be described in detail in this dissertation, and the EORTC-project. Finally, in the last approach a subjective measure is developed that allows the respondents to define their own domains. An example of this approach is the SEIQoL. All approaches have their pros and cons which are listed in a table by Kuyken and colleagues (see Table 1).

The second approach appeared to have the most disadvantages. It is this approach to which most projects belong. A number of years ago, an international project has been started aiming at the translation of the NHP into languages like Spanish or Swedish. This translation was prepared keeping in mind the many pitfalls one encounters when translating a questionnaire from one language into another (Hunt *et al.*, 1991). Another project was the International Quality of Life Assessment (IQOLA) Project (Aaronson *et al.*, 1992; Ware *et al.*, 1994). The aim of this project was to translate and adapt the SF-36 for use in 15 countries and to validate and provide norms in order to stimulate the employment in international studies of health outcomes. One of the reasons for starting this project was that the SF-36 appeared to be a good instrument in the US (Ware & Sherbourne, 1992). For instance, Brazier *et al.* (1992) reported that the SF-36 had good construct validity and was more sensitive to gradations in poor health than the EuroQol and the NHP.

Tüchler *et al.* (1992) developed a subjective QoL measure that can be used in clinical trials with cancer patients. They defined subjective QoL as "the self-perceived condition of a person which is expressed by a comprehensive evaluation of his/her life or a period of life on a positive-negative dimension" (p. 108). The instrument, called Questionnaire for Attitudes towards Quality of Health and Quality of Life (QAHL; Tüchler *et al.*, 1992), was developed using structured interviews and a grid-procedure. Subsequently, it has been made available in eight languages: Czech, German, Hungarian, Italian, Croatian, Polish, Romanian, and Slovakian. The QAHL is short (12 items), practicable and expandible (by adding other scales). Only four of the items were especially developed for this questionnaire, the other eight are derived from other measures. The QAHL was translated by physicians into their own language. The German and the English versions were both used as a point of departure. Then, the questionnaire was translated back into German by a native speaker or bilingual person. All inconsistencies were corrected (Tüchler *et al.*, 1992).

A project which used the third approach was that of the EuroQol group. This group has developed a short measure consisting of visual analogue scales measuring (i) health status, (ii) problems with walking about, (iii) problems with self-care, (iv) the ability to perform usual activities such as work, study, housework, (v) pain and discomfort, and (vi) anxiety or depression (EuroQol

group, 1990; Rosser & Sintonen, 1993). So far, the results indicate that the EuroQol is not a very good measure (e.g., Essink-Bot, 1995). Another project is that of the European Organization Research for Treatment of Cancer (EORTC) group and encompasses the development of a disease-specific measure for cancer patients, the EORTC-QOQC-30 (Aaronson *et al.*, 1993). This questionnaire is already described earlier in this chapter.

Table 1. Pros and cons of the four approaches (adapted from Kuyken *et al.*, 1994)

Approach	Pros	Cons
Developing an instrument for a particular purpose, population, and setting	<ul style="list-style-type: none"> - easier to get high levels of validity - easier to make it acceptable for the population 	<ul style="list-style-type: none"> - requires much resources - not immediately comparable across cultures
Taking existing measures from another setting and translating/adapting it	<ul style="list-style-type: none"> - relatively cheap - much known about psychometric properties of the instrument - results can be compared with the original setting 	<ul style="list-style-type: none"> - may lack culture-specific aspects for the new setting - may have aspects irrelevant for the new setting - translation is very important
Developing an instrument cross-culturally	<ul style="list-style-type: none"> - truly cross-cultural - good compromise between high validity and reliability in one setting and cross-cultural comparisons 	<ul style="list-style-type: none"> - difficult to coordinate
Individual specific measure	<ul style="list-style-type: none"> - real individual relevance - broad-ranging applications 	<ul style="list-style-type: none"> - in general not sensitive to change - respondents need to be able to have an insight in his/her QoL - the measure might elicit socially desirable answers - no detailed comparison possible between settings

The only project, known to the author, that falls within the fourth approach is the development of the SEIQoL. This questionnaire already has been discussed above.

1.4 Conclusion

QoL is a major topic which started to get attention in the 1950s. Initially used in large cross-sectional studies with mainly healthy respondents, today it has become incorporated in studies focussing on ill persons. This process started in the 1980s, when QoL was introduced in medical research with cancer patients. As a consequence of this increased attention for QoL, many instruments have been developed; mostly health status measures.

QoL is multidimensional and subjective. The term *subjective* usually refers to the fact that

respondents themselves answer questions regarding their health status and not their evaluations of behaviors or feelings.

The wide range of measures have made it difficult to compare results from various studies with each other. Although there slowly appears some consensus concerning multidimensionality and the constituting elements, almost everyone is still assessing QoL, or rather health status, in his or her own way. In addition, several of the core domains in health-related QoL may be of little relevance to well persons. Thus, health status measures that are exclusively based on domains such as physical functioning and self-care, may not be broad enough to provide an adequate assessment in well persons. Comparing the ill with the well then becomes very difficult (Patrick & Erickson, 1993).

In most studies, generic measures are used. However, an increasing number of disease-specific measures are being developed. There is still no standard questionnaire which may be included as a basic reference measure for QoL and which could be used with or without additional instruments in, for instance, clinical trials (Tüchler *et al.*, 1992). In spite of this lack of a *golden standard*, the SF-36 nowadays seems to get a very widespread use. However, as nearly all existing so-called QoL questionnaires, the SF-36 is in fact more of an objective health status measure.

As yet there is no questionnaire that fully measures subjective QoL. In most cases health status is assessed, but health status is not equivalent to QoL. In addition, only a small number of dimensions and aspects of QoL are measured. Furthermore, the definition used in the developmental phase of instruments is often unclear. Usually, the definition consists of a number of domains that will be assessed. In addition, every instrument has a different definition of QoL. So far, there is no international consensus about what QoL is and what it measures. Furthermore, the view point of individual researchers is often the starting point from which a particular instrument is constructed.

In addition, nearly all existing measures are developed in one language and subsequently translated into other languages. Even if an elaborate translation methodology has been used, then still this does not erase the fact that the measure was originally made to fit one culture and therefore will remain culture-specific, no matter how carefully translated. Also, measures might look psychometrically sound in another than the original language, but still miss aspects that are important in a 'new' language. One will never find out if this is the case unless researchers look at this possibility with an open mind and let lay persons tell them whether they are on the right trail. For, one does not know what is missing unless one looks for it (e.g., Bergner, 1985; Fletcher *et al.*, 1992). Another type of omission that might appear is that weights ascribed to aspects of QoL in one context might differ from the weights that persons in other contexts would

assign to the aspects (Fletcher *et al.*, 1992). Fletcher *et al.* (1992, pp. 1145-1146), have formulated this whole issue as follows: "Researchers should be wary of using an instrument in a cultural setting different from that in which it was developed. Apart from face or content validity, other problems include the validity of the translations and the relative importance of items in the instrument". Sartorius (1987) has said that cross-cultural studies underline the importance of four principles. The first is in line with the translation issue and states that no instrument for the assessment of psychological states is culture-free. In each instance, validity, objectivity, and other metric characteristics must be assessed in the culture of application. The equivalence of a question (and answer) in two different cultures is a *sine qua non* rather than a similarity of form in which it is asked or answered. The second principle is that the comparability of an item of information obtained in studies conducted in two or more cultures is limited in time because cultures change. The third principle states that long time that it takes before an instrument is ready, indicates that achieving equivalence of instruments across cultures and comparability of data takes time and a lot of patience. Finally, the fourth principle that emerges is that it is easier to communicate summary assessment from one culture to another than to translate detailed parts of an overall assessment.

Speaking of relative importance raises the next issue. In the traditional approach to QoL measurement it has always been assumed, especially regarding health status instruments, that different individuals perceive the same conditions in the same way (Browne *et al.*, 1994). Hence, this assumption has not been tested, although it is plausible that items of particular relevance to a group of respondents have been excluded (Fletcher *et al.*, 1992). Most existing measures fit the nomothetic approach. In a nomothetic approach the assumption is made that a single and common set of dimensions, scales or factors is equally applicable to all individuals with regard to their QoL. No account is taken of the essentially personal and subjective qualities which may be important for the QoL of one individual, but irrelevant for another (Fitzpatrick *et al.*, 1992; Stoker *et al.*, 1992).

Bergner (1985) mentioned another aspect of QoL assessments. Many measures have the terms *health* or *quality of life* in their name, which both have a positive connotation. However, when the content of the measures are considered, then, it appears that only the negative counterpole of these two terms is being measured. For instance, the Nottingham Health Profile (Hunt *et al.*, 1989) focusses on problems and does not reflect positive aspects. It might be that questionnaires with a positive connotation will elicit different results, because they also give the respondent the chance to indicate positive aspects of their lives.

The centres that were involved in cross-cultural studies were nearly always situated in Western countries, sometimes only in Europe. Moreover, some of the cross-cultural studies were aimed at

developing a disease-specific such as the EORTC for cancer. Thus, not all QoL questionnaires have the same scope.

For comparability across not only diseases but also across borders, there is a strong need for one universal definition of QoL and a cross-culturally developed instrument starting from this conceptualization. This instrument should include global items probing into various aspects of QoL, because in spite of repeated proposals to include global QoL measures, most questionnaires still lack global items (Tüchler *et al.*, 1992).

The WHO has started the project entitled 'The Assessment of QoL in Health Care' with the goal to develop cross-culturally a QoL instrument that measures QoL in a very broad sense. In this project, the subjective perspective is the focus of attention. This WHO instrument will encompass an extensive assessment of generic subjective QoL which will lead to the construction of a QoL scale that consists of global QoL items. According to Tüchler *et al.* (1992), this should be the starting point for all QoL measures.

The instrument of the WHO, called *World Health Organization Quality Of Life assessment instrument* (WHOQOL), will be applicable to healthy as well as patient groups and during the development of the instrument all the above mentioned shortcomings of the existing measures will be taken into account. The considerations for the WHO to start the large, cross-cultural study, some already mentioned above but repeated here to be complete, are the following. First, the fact that in recent years the focus in measuring health has been broadened to include more than just the traditional indicators of morbidity and mortality. Among the elements for which measures have been devised are the impact of disease and impairment on daily activities and behavior, perceived health, and disability/functional status. Such instruments, though they begin to provide a measure of the impact of disease, do not specifically assess QoL, which has been aptly described by Fallowfield (1990) as "the missing measurement in health care". Second, most measures of health status have been developed in a single cultural setting, and the translation of these measures for use in other settings is rather time consuming and in the majority of the cases unsatisfactory. During the translation of measures one should try to maintain conceptual, semantic, and technical equivalence (Sartorius & Kuyken, 1994). Third, the increasingly mechanistic trend in medicine, concerned only with the eradication of disease and symptoms, reinforces the need for the introduction of a humanistic element into health care. Health care is essentially a humanistic transaction in which the patient's well-being is a primary aim. The interest of WHO in assessing QoL arises from both a need for a genuinely international measure of this dimension of health and its commitment of continued promotion of a holistic approach to health and health care (WHOQOL group, 1994a; 1995a).

In this thesis, the development of the WHO instrument, the WHOQOL, will be described. In addition, the validity and reliability of the instrument will be discussed.

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CHAPTER 2 Background of the development of the WHOQOL¹

In 1991, the World Health Organization (WHO) started a cross-cultural project for the development of a quality of life instrument; the World Health Organization Quality of Life assessment instrument (WHOQOL). This WHO initiative is linked to other WHO projects concerned with topics such as the assessment of different treatments, the development and improvement of the WHO scheme of "impairments, disabilities and handicaps", and national guidelines for quality assurance in health care. Thus, the WHOQOL project is a part of a larger goal towards "Health for All" and the promotion of mental, social, and physical well-being (WHO, 1993a).

This project was started because, as already established in the previous chapter, at this moment there is no broad generic subjective QoL measure that is developed cross-culturally. The existing instruments are either disease-specific, culture-specific, measure only health status, or fail to cover the whole range of QoL aspects.

At the very start of the project, based on the existing literature concerning QoL, the following three assumptions were made. First, it was understood that the term QoL encompasses a broad entity. In other words, QoL was viewed as consisting of a wide range of facets. Second, a quantitative, reliable, valid, and responsive measure of QoL can be constructed and applied to various populations. These characteristics as well as ease of scoring and ease of administration are imperative to any (QoL) measure (Fitzpatrick *et al.*, 1992; Nelson & Berwick, 1989). Third, any factor affecting QoL would influence a wide range of components covered by the instrument (WHO, 1993a).

The aim of the project was to develop a QoL instrument that (i) resulted from one definition of QoL, (ii) would be applicable to healthy as well as stressed persons (stress caused by a disease or a difficult situation), and (iii) would be simultaneously constructed in several different countries all over the world. At the same time the instrument had to be comparable across different cultures/languages.

In view of the aim of the project, the field centres that joined the project had to provide differences in their levels of industrialization, available health services, and other markers relevant to the measurement of QoL such as role of the family, perception of self, and dominant religious denomination (WHO, 1993a). The centres that joined the project from the start were Melbourne, Australia; Zagreb, Croatia; Madras, India; Tilburg, the Netherlands; Panama City, Panama; St.

¹ This chapter is based on the WHOQOL study protocol (WHO, 1993a).

Petersburg, Russia; Bangkok, Thailand; Bath, UK; Seattle, USA; and Harare, Zimbabwe.

In the next paragraph, the definition of QoL used in this project will be discussed. Subsequently, the structure of the instrument will be explained. In addition, the proposed uses of the WHOQOL will be outlined. The last part of this chapter will encompass the steps in the developmental process of the instrument.

2.1 Defining quality of life

Over the course of three meetings with QoL experts from around the world², a working definition of QoL was agreed upon. In this project, QoL was defined as persons' perception of their position in life within the context of the culture and value systems in which their lives and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept incorporating, in a complex way, the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment (WHOQOL group³, 1994). This definition of QoL differs from nearly all existing definitions. As already mentioned in the previous chapter, Andrews (1991) defined QoL in terms of how individuals themselves, evaluate their lives. This covers the subjective intention of the WHOQOL definition (a person's perceptions of his/her position in life) but leaves the cultural aspects out of its scope. In addition, in Andrews's definition it is explicated which aspects of life people should evaluate. Earlier, in 1976, Andrews in collaboration with Withey defined QoL as "not just a matter of the conditions of one's physical, interpersonal and social setting but also a matter of how these are

² April 1991, Geneva (WHO, 1991); February 1992, Geneva (WHO, 1992a); June 1992, Geneva (WHO, 1992b).

³ The WHOQOL group consists of a coordinating group, collaborating investigators in each of the field centres, and a panel of consultants. The coordinating group is directed by Dr. J. Orley, Division of Mental Health, WHO. The field centre collaborating investigators are: Prof. H. Herrman, Dr. H. Schofield, and Mrs B. Murphy, University of Melbourne, Australia; Prof. Z. Metelko, Prof. S. Szabo, and Mrs. M. Pibernik-Okanovic, Institute of Diabetes, Endocrinology and Metabolic Diseases and Department of Psychology, Faculty of Philosophy, University of Zagreb, Croatia; Dr. N. Quemada and Dr. A. Caria, INSERM, Paris, France; Dr. S. Rajkumar and Mrs. S. Kumar, Madras Medical College, India; Dr. D. Bar-On and Dr. M. Amir, Ben-Gurion University, Beer-Sheva, Israel; Dr. M. Tazaki, Department of Science, Science University of Tokyo, Japan, and Dr. A. Noji, Department of Community Health Nursing, St. Luke's College of Nursing, Japan; Prof. G.L. Van Heck and Mrs J. De Vries, Tilburg University, The Netherlands; Prof. J. Arroyo Sucre and Prof. L. Picard-Ami, University of Panama, Panama; Prof. M. Kabanov, Dr. A. Lomachenkov, and Dr. G. Burkovsky, Bekhterev Psychoneurological REsearch Institute, St. Petersburg, Russia; Dr. Y. Bodharamik and Dr. K. Meesapaya, Institute of Mental Health, Bangkok, Thailand; Prof. S. Skevington, University of Bath, United Kingdom; Dr. D. Patrick, Ms. M. Martin, and Ms. D. Wild, University of Washington, Seattle, USA; Prof. W. Acuda and Dr. J. Mutambirwa, University of Zimbabwe, Harare, Zimbabwe. The international panel of consultants consists of: Dr. N.K. Aaronson, Dr. P. Bech, Dr. M. Bullinger, Dr. He-Nian Chen, Dr. J. Fox-Rushby, Dr. C. Moinpour, Dr. M. Power, Dr. R. Rosser, and Dr. N. Sartorius. Consultants who have advised WHO at various stages of the development of the project have included: Dr. D. Buesching, Dr. D. Bucquet, Dr. L.W. Chambers, Dr. B. Jambon, Dr. C.D. Jenkins, Dr. D. De Leo, Dr. L. Fallowfield, Dr. P. Gerin, Dr. P. Graham, Dr. O. Gureje, Dr. K. Kalumba, Dr. F. Kerr-Correa, Dr., C. Mercier, Mr. J. Oliver, Prof. Y.H. Poortinga, Dr. R. Trotter, and Dr. F. van Dam.

judged and evaluated by oneself and others" (p. 12). This conceptualization of QoL comes closer to the WHOQOL definition because not only the subjective angle is mentioned, but also some aspects of life like the physical, interpersonal and social aspects. However, again here the cultural aspect is not mentioned. Finally, the definition of QoL by De Haes (1988, p. 7) "the subjective judgment of the good and satisfying nature of life as a whole" does not refer to the context of culture and value systems. Furthermore, the latter definition is too vague. Thus, the WHOQOL definition of QoL is new in that it takes the culture and value systems of a person into consideration. In addition, the definition incorporates the view which will be the point of focus in the questionnaire: the perception of the individual. Finally, the QoL definition is in accordance with the WHO's definition of health which states that health is 'a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity' (WHO, 1958).

The WHOQOL definition of QoL definition reflects the view that QoL refers to a subjective evaluation, which is embedded in a cultural, social, and environmental context. Although a few researchers already have noted these aspects (e.g., Bergner, 1985), it is the first time that they are incorporated into a definition. Although many researchers think otherwise, QoL is related but cannot simply be equated with terms like *functional status* or *health status*, *life satisfaction*, *happiness*, *mental state*, or *well-being*. The reason being that QoL is more than psychological, social, and/or physical aspects of functioning. As Ware (1991, p. 776) has put it: "It has become fashionable to talk about functional status and well-being as if they were synonymous with quality of life. Quality of life, however, is a much broader concept". Implicitly, a similar idea was voiced by Padilla, Mishel, and Grant (1992, p. 156) who said that QoL "incorporates the dimensions of psychosocial well-being, physical well-being and disease and treatment-related distress". Fernandez and Kulik (1981) used health status as an independent variable in a regression analysis where life satisfaction was the dependent variable. It appeared that self-reported health status was the best predictor of life satisfaction. The correlation between the two variables was 0.30. To further explain this idea, definitions of a few related terms will be given.

Functional status 'refers to behavioral dysfunctions due to health problems' (Ware, 1991).

Functional status refers to the performance of (or the capacity to perform) a variety of activities that are normal for most people (Aaronson *et al.*, 1987).

Health status is the clinical disability caused by the disease (Stoker, Dunbar, & Beaumont, 1992).

Happiness is ... the degree to which an individual judges the overall quality of his life favorably. In

other words: how well he likes the life he leads (Veenhoven, 1991).

Happiness is a sense of psychological well-being (Bradburn, 1969).

Precisely stated, health status is the product (expected value) of the social preferences assigned to levels of function and the probabilities of transition among the levels over the life expectancy of an individual or a group (Patrick, Bush, & Chen, 1973).

Well-being includes psychological distress, psychological well-being, and life satisfaction (Ware, 1991).

Well-being was equated with psychological adjustment by Pfeiffer and Wetstone (1988).

"global" well-being, that is, happiness or satisfaction with life-as-a-whole or life in general (Andrews & Robinson, 1991).

QoL is even distinct from health-related QoL which can be defined as "optimal levels of mental, physical, role ... and social functioning, including relationships, and perceptions of health, fitness, life satisfaction, and well-being. It should also include some assessment of the patient's level of satisfaction with treatment, outcome and health status and with future prospects" (Bowling, 1995, p. 3). Thus, the major difference between QoL and related concepts is its breadth. In contrast to related concepts, in the case of QoL there is also room for environmental and spiritual aspects. So, QoL is a *multidimensional* concept incorporating the individual's perception of all kinds of aspects of life (WHO, 1993a).

2.2 Structure of the instrument

Following the definition of QoL, a *provisional* list of domains and constituent facets of QoL was developed by the group of experts. The six domains, also referred to in the QoL definition, were called Physical domain, Psychological domain, Levels of Independence, Social Relationships, Environment, and Spiritual domain. In its turn, each domain was operationalized through facets. For instance, the Physical domain included facets like Pain and Discomfort and Sensory Functions (see Appendix I which contains the provisional list of domains and facets).

For each facet a complete facet definition was written which consisted of a conceptual definition written in prose, a description of various indicators or dimensions along which a rating could be made for that facet, and a listing of some example situations or conditions that might significantly affect that facet at various levels of intensity. An example of a facet definition is shown in Table

1. The other facet definitions are listed in Appendix II. As can be seen, a definition was written in simple words to ensure comprehensibility and translateability. In addition, it reflects the aspects that may and may not be included in the questions of that facet. All definitions had a standardized format in order to suggest the structure and content for questions according to the scheme: what the facet explores, what the questions should include, and some examples.

The writing of facet definitions was done following three stages. First, the literature and existing questionnaires were reviewed (WHO, 1992b). This helped to establish how a particular domain or facet was defined by others in the QoL field. Second, the definitions had to fit into the conceptual framework of the project. Third, dictionaries and guides relating to health or psychological states - were used in writing the definitions (WHO, 1993a).

Table 1. Definition of the facet Pain and Discomfort (WHOQOL group, 1995a)

This facet explores unpleasant physical sensations experienced by a person and, the extent to which these sensations are distressing and interfere with life. Questions within the facet include the control the person has over the pain and the ease with which relief from pain can be achieved. The assumption is made that the easier the relief from pain, the less the fear of pain and its resulting effect on quality of life. Similarly changes in levels of pain may be more distressing than pain itself. Even when a person is not actually in pain; either through taking drugs or because the pain is by its very nature on and off e.g. migraine, his/her quality of life may be affected by the constant threat of pain. It is acknowledged that people respond to pain differently, and differing tolerance and acceptance of pain is likely to affect its impact on quality of life.

Unpleasant physical sensations such as stiffness, aches, long-term or short-term pain, or itches are included. Pain is judged to be present if a person reports it to be so, even if there is no medical reason to account for it.

Examples:

- * A person with intermittent severe migraine with possible threat of severe pain as the major feature.
- * A person with chronic rheumatoid arthritis.

The facet depicted in Table 1, Pain and Discomfort, is a *subjective perception or experience*. In contrast, Vitality and Fatigue, also belonging to the Physical domain, is defined as a *state*, whereas Mobility, a facet of the domain Level of Independence, was defined as a *capacity* (being able to move around). Thus, facets were described in a variety of ways: in behavioral terms, as a state of being, a capacity or potential, or a subjective perception or experience.

After the first draft of the definitions was finished, they were sent to all 15 field centres. This was done to provide the centres with the opportunity to review the applicability and local appropriateness. In addition, the centres could indicate any translation problems that they expected. Following the comments from different centres the facet definitions were revised in Geneva.

2.2.1 Types of questions

Initially, it was decided that each facet in the instrument would contain three different levels of questioning about QoL. These types of questions were called *perceived objective*, *self-report subjective*, and *importance questions*. All three type of questions should be written in general terms and should be global. In addition, the perceived objective and self-report subjective questions should be self-assessments of a person’s QoL.

Table 2. Levels of assessment for the WHOQOL instrument

	Perceived objective	Self-report subjective	Importance
Description	Global evaluations of behaviors, states or capacities. Questions at this level assess a persons reporting of their physical and psychological health, level of independence, social relationships and environmental conditions.	Perceived satisfaction / dissatisfaction with behavior, state or capacity. i.e. How well are a person’s needs and requirement met, and how much does a problem or difficulty prevent them from doing what he/she wants to do?	Perceived importance. i.e. How important is the facet to the person’s quality of life? This should be established even if the person has had no difficulties in this area within the time frame of the instrument. Questions will be in a standardised form across field centres.
Example Question	How do you sleep?	(i) Are you satisfied with your sleep? (ii) How much do any difficulties with your sleep interfere with doing what you need to do and would like to do?	For positively framed facets: How important to you is restful sleep? For negatively framed facets: How important to you is it to be free of pain and discomfort?
Example of Rating Scale	Excellently / Very well / Well / Fair / Poor	(i) Very satisfied / Somewhat satisfied / Neither satisfied nor dissatisfied / Somewhat dissatisfied / Very dissatisfied (ii) Not at all / A little / Somewhat / Quite a bit / Extremely	Most important / Very important / Somewhat Important / A little important / Not important

Perceived objective questions were global evaluations of behaviors, states, or capacities. Perceived satisfaction or dissatisfaction with a particular behavior, state or capacity would be measured by the self-report subjective questions. To investigate whether these two types of questions could be differentiated from each other, two persons (independent WHO staff members) were given a list of 37 random questions consisting of the two types of questions. These questions were selected from the entire pool of questions that the centres had extracted from the focus group work. Independently, the two persons had to classify the 37 questions as being a perceived objective or a

self-report subjective question. They had to use the definitions of these types of questions as presented in Table 2. The interrater reliability appeared to be good (81.1% agreement). Based on this result, it was concluded that the two types were probably distinct from each other. The importance questions would assess perceived importance (see Table 2). Each facet should have questions for all three types.

Furthermore, it was decided that the WHOQOL would not include questions based on *objective* measurement of the individual's health and functional status, for instance, usual amount of sleep. The reason being that there exist already many health and functional status measures (see Chapter 1). However, objective measures can be used together with the WHOQOL (WHO, 1993a).

Perceived objective questions would tend to be addressed by intensity and frequency questions. On the other hand, self-report subjective questions would primarily consist of evaluation questions.

2.2.2 Types of response scales

Aside from the intensity, frequency, and evaluation of states or behaviors scales, the WHOQOL also contains capacity scales. The intensity response scale refers to the degree or extent to which a person experiences a state or situation, for instance, the intensity of pain. Questions may also refer to the vigor or strength of a behavior. The assumption is that the experience of a more intense state is associated with corresponding changes in QoL. Example questions include: "How trapped do you feel by pain or discomfort?" and "How much does anxiety restrict your everyday life?". The anchors for the intensity scale are *Not at all* and *Extremely or An extreme amount*.

The capacity response scale refers to a capacity for a feeling, state, or behavior. The assumption is that a more complete capacity is associated with a higher QoL while a limited capacity is related to a lower QoL. Example questions include: "How well are you able to understand others?" and "How confident do you feel with other people?". The anchor points are *Not at all* and *Completely*.

The frequency response scale refers to the number, frequency, commonness, or rate of a state or behavior. The time frame is crucial to these questions, such that the frequency refers to its frequency in the specified time period. The assumption is that a greater number of occurrences of the state or behavior is associated with positive or negative changes in QoL. For instance, when a person is frequently tired, it is expected that his/her QoL will decrease whereas when someone is very energetic most of the time, his/her QoL will increase. Example questions are: "How often do you leave things undone because of tiredness?" and "How often do you worry about your health?". The anchor points are *Never* and *Always*.

The evaluation response scale differs from the other response scales in that it has a neutral midpoint and the anchor points are not extreme points in order to maximize full usage of the scale. This response scale refers to the appraisal of a state, capacity or behavior. The assumption is that a

more positive evaluation is associated with a corresponding increase in the respondent's QoL. Example questions are: "How happy are you with the amount of alcohol you drink?"; "How satisfied are you with the degree to which you can count on you family and friends?"; and "How good are the personal relationships in your life?". Several evaluation scales are employed. The anchor points are *Very happy-Very unhappy*; *Very satisfied-Very dissatisfied*; and *Very good-Very poor*. In several languages (e.g., Dutch) the distinction between the two question stems "How satisfied ...?" and "How happy ...?" cannot be translated or is not acceptable. Therefore, all the questions beginning with "How happy ..." would become "How satisfied ...?".

The questions which make up the WHOQOL have arisen from a process designed to capture both the culture-specific meaning and operationalization of QoL facets as well as language idiom. For this reason there was originally space for some diversity in the nature and structure of the questions. It was thought that consequently, there had to be a trade-off between a minimum number of standardized question-response scale formats while there was still room for an enquiry into difficult aspects of QoL, and thus maintaining the unique face validity of the questions in the WHOQOL in different cultures (WHO, 1993b). However, as will be discussed in chapter 5, this a priori possibility for differences between the WHOQOL at question level appeared not to be needed. For each centre the same questions emerged on top after analyses.

Furthermore, it was tried to use questions and instructions for the different response scales which are clear and acceptable for the respondents.

2.2.3 General features of the instrument

Other characteristics of the instrument are concerned with issues such as time frame and different versions of the questionnaire. In general, the time frame employed in the instrument was two weeks. However, for particular uses of the instrument different time frames may be necessary. For instance, in the assessment of QoL in chronic conditions such as arthritis, a longer time frame such as four weeks may be preferable. In the assessment of patients receiving chemotherapy, the treatment cycle should be considered in order to establish and control for possible responsiveness and side effects. Furthermore, the perception of time can vary from one cultural setting to the next and in the interpretation of data this is something that should be explicitly acknowledged.

In order for the instrument to be comparable across different cultures/languages, the structure of the WHOQOL had to be derived from work in numerous centres around the world and as such had to demonstrate universality. In addition, a common methodology had to be used to develop and derive questions in each culture/language. Furthermore, it was allowed that questions varied for different cultural settings, so-called *national* questions. However, these questions would have to compete with the questions from all other centres that emerged after extensive field work with the

pilot instrument in each field centre. Only when these national questions would come out on top after meeting particular psychometric criteria (which are outlined in Chapter 5), they would be included in the instrument. Thus, a national question from the Tilburg centre had to demonstrate to be a better question for that centre than the questions from the global question pool.

As appeared in the definition of QoL, the instrument had to measure *subjective* QoL. Because the instrument would be focused on the respondents' perception, it was expected to measure the *effects* of disease and health interventions on QoL rather than health status aspects.

In order to make sure that the cultural and value systems mentioned in the QoL definition would be reflected in the instrument, it was decided that the questions of the instrument were allowed to be different from one field centre to the next.

It was decided that the instrument should be governed by the needs of health professionals and researchers. Therefore, several versions of the instrument were developed (WHOQOL group, 1994). In principle, the WHOQOL will be self-administered. However, if a respondent is not capable to read or write due to cultural, educational, health reasons, or because he/she is nervous about completing a questionnaire (Fletcher *et al.*, 1992), an interviewer-assisted or interviewer-administered approach will be used. This means that apart from a regular self-administered approach of the WHOQOL, guidelines have been developed for two additional approaches: an interviewer-assisted and an interviewer-administered approaches⁴. However, whenever possible the subject will have to give his/her own response to the questions, because it is well known that others, for instance, doctors and parents are, in general, not valid proxies for the patient's opinion about his/her functioning, well-being, or other aspects of the QoL (Bernheim, Ledure, Souris, & Razavi, 1987; Pearlman & Uhlmann, 1988; Ware, 1991). It must be added that it is dependent on the domain that is assessed and the type of questionnaire (health status or subjective QoL) whether or not the correspondence between respondent and proxy is adequate or not (Patrick & Erickson, 1993). Furthermore, a long as well as a short version of the instrument should be developed. This should be done keeping in mind that the length of a questionnaire is an important issue. For reasons of practicability and usability the shorter the measure the better. However, a brief measure will loose on every test concerning relative precision and other psychometric properties (McHorney, Ware, Rogers, Raczek, & Rachel, 1992; Ware, 1991). The longer version will be useful when a comprehensive inquiry into QoL requires a relatively lengthy assessment. In the short version only primary facets of QoL will be addressed. Primary facets will be the ones that appear to be the most important for a person's QoL. These primary facets may be detected using multiple regressi-

⁴ Guidelines for use of the WHOQOL-100 as an interviewer-assisted/-administered questionnaire are presented in the report of the meeting of the WHOQOL group in Montreal (WHOQOL group, 1995b).

on analysis. The short version of the WHOQOL increases the instrument's utility. It will be particularly useful in repeated measures research designs, in clinical settings and whenever respondents have difficulty in completing the long version (WHOQOL group, 1994). Thus, the instrument will have high "application potential" (Bullinger, 1993).

The intention of the WHOQOL researchers was that it would be possible to produce a QoL profile. With such a profile it is possible to have (i) an *overall* QoL score; (ii) a *domain* score; and (iii) a *facet* score. However, the overall QoL score should not be used in isolation, but always in combination with at least the domain scores. The reason is that summing disparate dimensions might elude contradictory trends for different aspects of QoL (Fitzpatrick *et al.*, 1992). In other words, a single summary score limits the clinical usefulness of health indexes, unless the score can be broken down into its components to allow identification of the areas in which change has taken place (Fletcher *et al.*, 1992).

The importance questions can be used in three ways. First, they can be used within a country to detect whether or not a shift has taken place in importance of particular facets. Second, they can be used to compare the importance of facets across cultures or countries. It is quite feasible that a facet that is important for people living in India may not be so very important in The Netherlands. Finally, the importance ratings can be used to see whether there is a difference in importance of facets between various disease groups or between well and ill groups. In other words, one might be interested in differences at the group level within one particular setting.

Given all the characteristics of the WHOQOL mentioned above, a number of possible uses of the instrument will be listed in the next paragraph.

2.3 Uses of the instrument

It is anticipated that the WHOQOL will have numerous uses at the international as well as the national/regional level.

At the international level, the availability of an international QoL assessment instrument such as the WHOQOL will make it possible to carry out relevant research in a number of centres and to compare the results obtained in different parts of the world. Such research has important benefits, permitting questions to be addressed that would not be possible in single-site studies. For example, a comparative study in two or more countries on the relationship between health care delivery and QoL requires an assessment yielding cross-culturally comparable scores. Sometimes accumulation of cases in QoL studies, particularly when studying rare disorders, is helped by gathering data in several settings. Multicentre collaborative studies can also provide simultaneous multiple replications of a finding, adding considerably to the confidence with which research results can be accepted. The availability of a cross-culturally comparable QoL measure will also facilitate comparative

international epidemiological studies; thus, furthering the understanding of diseases and the development of treatment methods (WHOQOL group, 1994).

At the national/regional level it is anticipated that the WHOQOL will have multiple applications in clinical practice, research, audit and health policy planning, and evaluation. For clinical practice the instrument can assist the physician's understanding of how a disease affects a patient's QoL. A direct impact of the questionnaire on health care could be in the individual encounters between doctors and patients (Winslow, 1992). Thus, the instrument can help the clinician in making judgements about the areas in which a patient is most affected by disease. This can assist the doctor in making treatment decisions and will also change and improve the interaction between patient and doctor. This will give more meaning and fulfillment to the work of the doctor and should lead to the patient being provided with more comprehensive health care. Because a comprehensive form of assessment, covering different aspects of patients' functioning is being carried out, patients themselves may find their health care more meaningful. Furthermore, when the WHOQOL is used together with other measures, it will allow the assessment of changes over the course of treatment. Routine use of QoL instruments such as the WHOQOL will also enhance the recording of patient data, and enable communication of valuable information between professionals. In some developing countries, where resources for health are limited, treatments aimed at improving QoL can be both effective and inexpensive.

Concerning the application of the WHOQOL in research it is anticipated that the instrument will be of considerable use in clinical trials, in establishing baseline scores in a range of areas, and looking at changes in QoL over the course of treatment, particularly where disease prognosis is likely to involve only partial recovery or remission, and treatment may be more palliative than curative. For epidemiological research, the instrument will allow detailed QoL data to be gathered on a particular population, and used for predicting morbidity and mortality.

In the implementation and planning for new policies it is important that the rationale for and effect of policy changes on QoL of people in contact with health services is evaluated. An instrument such as the WHOQOL will allow the planning and monitoring of such changes. That the instrument was developed cross-culturally will allow health care providers, administrators and legislators to be confident that data yielded by work involving the instrument is genuinely sensitive to the cultural climate. Similarly, in the periodic review of the completeness and quality of medical services, the WHOQOL will provide an invaluable supplementary appraisal of health care service and patients' QoL. It is a measure of patients' perception of the quality and availability of health care (WHO, 1993a).

Thus far, concept clarification involving the establishment of an agreed upon definition of QoL and an approach to international QoL assessment has been discussed. In addition, aimed general

properties of the instrument have been depicted. The stages in the development will now be outlined.

2.4 Steps in the development of the instrument

The development of the WHOQOL was undertaken following a number of steps. First, preliminary focus groups were conducted to examine the cross-cultural relevance of the existing list of domains and facets, and to establish which facets are felt to be awkward or difficult to talk about in each cultural setting. After the facets were translated⁵ into local languages, focus groups were conducted in order to generate potential questions for the pilot version, to provide preliminary importance ratings for each facet, and to assess further the validity and comprehensibility of the existing facet list. Taking the focus group reports, questions were generated and the pilot instrument of the WHOQOL was made. After the pilot questionnaire was administered, the WHOQOL-100 was developed. This instrument was then tested for reliability, validity, and responsiveness.

The WHOQOL development process has three unique features. First, it involves a simultaneous and collaborative approach to devising an international instrument in several culturally diverse settings. In this way a genuinely international measure is made, because the researchers from all centres were involved in every stage of the process of instrument development. During the entire development process, standardization, equivalence among settings, and translation issues have been emphasized.

The second unique feature of the development of the WHOQOL is the iterative input of QoL researchers and the consolidation and revision of this information at the grassroots level at each stage. This ensures that existing expertise in QoL assessment, the views of practicing health professionals, and the ideas of patients are represented in the construction of the instrument.

Third, a tried and tested WHO translation method was used in the WHOQOL project. It is a technique of forward and backward translation completed by an iterative review process by monolingual and bilingual groups to ensure conceptual, semantic, and technical equivalence (see Appendix III). This translation methodology is used throughout the development process (WHOQOL group, 1994).

In accordance with the development of the WHOQOL as outlined above, the topic of the next chapter will be preliminary focus groups.

⁵ The translation into the local language was done by bilinguals. Back translation into English was done by a professional native translator. See Appendix III for the entire translation methodology.

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CHAPTER 3 Preliminary focus groups

As a first step in the development of the WHOQOL, once the provisional facet structure and set of facet definitions had been agreed upon, semi-structured discussion groups, called *preliminary focus groups*, were conducted at each of the field centres. In these preliminary focus groups participants were asked to report on how each facet affected their QoL. Furthermore, they were asked to generate a list of areas which they felt contributed to QoL. In this way, the cross-cultural relevance of the existing list of domains and facets was examined. In addition, it was discussed whether certain facets were difficult to talk about in a particular cultural setting. The way in which the groups were conducted and the results of these group meetings are the topic of this chapter. First, the goals of this qualitative research using focus groups will be presented. Then, after a description of the procedure, the Dutch data are presented as an example. Subsequently, the global results are discussed. Finally, the new structure of QOL was checked with the help of participants of the preliminary focus groups by means of a pile sorting task.

3.1 Aim of the preliminary focus groups

In each field centre, two preliminary focus groups were conducted. The purpose of running these groups was twofold. The first aim was to determine, describe and weight specific facets judged to be important to quality of life within a particular culture. The second aim was to group these facets into a small number of broad areas (domains) and to describe these domains. Thus, the preliminary focus groups had to provide an independent check on the list of domains and facets made by the consultants and principal investigators of the centres. The objectives of the preliminary discussion groups were:

- (i) to generate a list, along with brief descriptions, of specific facets judged to be important to QoL;
- (ii) to provide importance ratings for each of these facets;
- (iii) to generate a number of more general areas, called domains, judged by the participants to involve the generated facets that contribute most to quality of life within the particular cultural setting; and
- (iv) to get an idea of how easy it would be to talk about each of the facets within the particular cultural setting.

For the purposes of this stage of the project a focus group was defined as a discussion group

designed to obtain in a cultural group the dominant perceptions about QoL using a group of individuals who are as much as possible representative of that cultural group. The focus groups were to be carried out in a nonthreatening and enjoyable way so as to obtain the most detailed and valid information about QoL.

3.2 Method

The participants were recruited via an advertisement in a local newspaper. This newspaper was chosen because of its door-to-door deliverance in the region of Tilburg. People had to send in a postcard if they wanted to participate in one of the two discussion groups.

In order to give people who work the opportunity to participate, one group was held in the evening. The second group was scheduled on a wednesday morning. The groups were run by a focus group moderator and an assistant. The interview schedule used for these discussion groups is listed as Appendix IV.

3.2.1 Subjects

The first group, subsequently referred to as Group 1, consisted of six participants; four women and two men. The age range was 19 to 71 years. The level of education ranged from high school to university. One woman (unmarried; 19 years of age; 12 years and three months of fulltime education) had a heart disease, poor vision, and food allergies. The second woman (married; 51 years of age; 10 years of fulltime education) had a husband with diabetes mellitus and a mother with dementia. The husband of the third woman (widow; 71 years of age; 19 years of fulltime education) had died of skin cancer and she was herself handicapped. The last woman (married; 49 years of age; 13 years of fulltime education) in this group had severe mobility problems. One man (married; 53 years of age; 18 years of fulltime education) had diabetes mellitus. The last participant (male; unmarried; 28 years of age; 18 years of fulltime education), a general practitioner in training, was interested in QoL because of his education and future occupation.

The other group, called Group 2, had four participants: three females and one male (age range 34-66 years; the lowest level of education was secondary vocational training and the highest level of education was university). The man in this group (divorced; 61 years of age; 14 years of fulltime education) suffered from Parkinson's disease. One woman (married; 34 years of age; 16 years of fulltime education) had a muscular disease. The two other women participated only because the subject interested them. One of them was unmarried, 66 years of age, and had received 16 years of education. The other woman was married, 43 years of age with 20 years of fulltime education. In both preliminary focus groups, the participants made a more or less equal contribu-

tion.

3.2.2 Procedure

During the two sessions the following questions formed the core of the meetings.

1. What are words or phrases which describe quality of life?
2. What are the things which affect people's quality of life?
3. Are there things that we have mentioned that you think are important to quality of life that people find it difficult to talk about?
4. Are there any other important facets which have not been covered?
5. How important is each of the facets mentioned?
6. Are there more general levels which include some of the things you have mentioned which affect quality of life?

The outcome on all of these questions will be discussed below using the Dutch preliminary focus group outcomes as an example.

3.3 Dutch results

In Group 1, all kinds of terms/phrases were mentioned when the participants were asked to generate words that describe QoL. The list (see Table 1) has an overlap with the facets listed by the experts (see Appendix I).

Table 1. Terms and phrases that describe QoL; Group 1

1.	Independence
2.	Being self-supporting ¹
3.	Adequate use of senses
4.	Being able to live without limitations
5.	Happiness
6.	Freedom
7.	To do what you want to do
8.	Being with people who you can talk to and in which company you can be yourself
9.	Successful adaption to (new) shortcomings
10.	Being inventive in finding ways to do things that are difficult to do when having a particular disease
11.	Feeling as if "your house is burning down"; wanting to do things and being alive while your body (i.e., house) is breaking down
12.	Having to think more of restrictions and possibilities instead of just doing something
13.	Obsession with disease and limitations due to the disease
14.	Resisting shortcomings. Trying to do as many things as possible; not wanting to adjust to the illness; not wanting to accept the limitation

¹ The word "self-supporting" is an inadequate translation from the Dutch word "zelfstandigheid". The Dutch term does not only refer to the financial domain but to all areas of life, such as being able to live on one's own without the help of someone else.

In Group 2, one participant said that, for her, quality meant "how you handle your being". All participants agreed that QoL can be defined as "the meaning of life". Other terms used for QoL are presented in Table 2.

Table 2. Terms and phrases that describe QoL; Group 2

1.	Well-being
2.	Satisfaction
3.	To do what you want to do
4.	The influence of your environment on your life (social as well as material; like house)
5.	Learning to cope with the negative points of disease/life and having a goal or meaning despite all this
6.	Looking for positive things
7.	Having good (accessible) facilities; public and home
8.	Being able to educate yourself ("watching courses on television")
9.	Being self-supporting ¹
10.	Work
11.	Enough money to pay for things that enhance QoL
12.	Relaxation/recreation is limited by illness or the illness of the partner or a member of the family

From the above it appears that there are a number of terms and phrases that came up in both groups such as *self-supporting*, *to do what you want to do*, *social environment* and *learning to live/cope with negative aspects or limitations*. In both groups feelings or emotions were mentioned; be it different ones. Examples of emotions mentioned are *happiness* and *satisfaction*.

In general, both groups took a different path. Group 1 mentioned predominantly cognitive aspects of QoL. The topics were mainly feelings and coping. In Group 2 material matters or facilities was a major topic besides mentioning feelings and coping.

The next question that was posed in the separate groups was "Are there more general levels which include some of the things you have mentioned which affect quality of life?". In both groups the generated facets, which were shown on a flip-over, were used as a starting point in the discussion that followed. From the *facets* the participants arrived at some broad *domains* of QoL. Each idea was elaborately discussed until all participants understood what was meant by the suggested broad categories. When a majority of a group agreed that a suggestion was good, it was written down on the blackboard.

According to Group 1, the core of QoL consisted of independence, also labelled negatively in terms of limitations, and being self-supporting. All participants agreed fully with this view. Independence can be divided into two parts. One part is (in)dependence of/on others in whatever way. The second part is (in)dependence with respect to self, for instance, being restricted by sight

or lack of energy. Here, the question is whether or not one has control over objects or actions. Being self-supporting was seen as strongly linked with independence. The domains that came out as most important were: *independence* and *control*. These two domains can be put in a 2-by-2 matrix as follows.

	Self	Other(s)/Environment
control		
no control		

Terms that appeared to divide the facets are *subjective* versus *objective*. Examples of subjective facets are emotions and expectations. Examples of objective facets are the quality of the senses, work, and mobility.

Individual vs *general* is another dimension that had relevancy for all the facets. Individual facets are, for instance, happiness or other emotions. General facets are facets such as pain and mobility. Individual refers to the fact that, for example, happiness is a personal evaluation which can differ from one person to the other. However, *general* refers to the fact that it is a known fact that, for instance, persons who suffer from a certain condition all have pain.

Physical versus *psychological* is a third broad dimension that was suggested. Mobility, availability of health care and the use of one's senses are examples of the physical aspect. Expectations for the future and anger are examples of the psychological side of QoL.

According to Group 2, the more general classes in which the facets could be grouped were:

1. *Social environment*;
2. *Material aspects* (e.g., money and facilities), also called '*natural environment*';
3. *Mental aspects* such as emotions;
4. *Physical aspects*; and
5. *Goals* such as activity, planning, and giving a meaning to life or more specific to an illness.

This group also made a higher level distinction between *micro* and *macro* aspects. For instance, sexuality was conceived of as a micro aspect, while public facilities and meaning of life were considered to be aspects at the macro level.

It is apparent that both groups had a totally different approach to the classification of the facets

in terms of broader domains. Group 1 made distinctions between facets predominantly using very general levels. They came up with several antagonistic groupings. Group 2 made a more refined distinction in five different domains. This group also made one distinction at a very general level.

Subsequently, the participants were asked to name aspects of QoL and then rate the importance of each facet of QoL that was mentioned in the group. In Group 1, a long list of facets was mentioned. After they finished brainstorming, the facets were written down on a flip-chart. Then, the participants had to give an importance rating of each facet. They had to give ratings ranging from '1' (*Not very important*) to '3' (*Very important*). This was done orally. The ratings that resulted represented more or less the average rating for the members of the group. When group members could not make up their minds about the importance of a facet or when no consensus could be reached, the competing ratings were all written down. The results are shown in Table 3.

Table 3. Facets of QoL; Group 1

No.	Facets	Importance rating
1.	Peace, balance	3
2.	Use of one's senses	3
3.	Happiness	3
4.	Independence	3
5.	Emotions/feelings (negative), consisting of anger, anxiety, depression, sarcasm, cynism, frustration	3
6.	Mobility (ability to move and transport)	3
7.	Pain	3
8.	Self-confidence (also physical)	3
9.	Social contacts, including family, friends, acquaintances	3
10.	Being able to give meaning to the disease itself, e.g., why one has the disease, and being able to give meaning to one's life	3
11.	Good communication with doctor(s)	3
12.	Information about the disease	3
13.	Perceived availability of health care	3
14.	Sexuality	3
15.	To be able to express oneself, e.g., in painting, reading, or writing. It also means, e.g., smoking (a kind of addiction)	3
16.	Attention directed at one's own finiteness (has to do with anxiety)	2/3
17.	Belief in God or mystical object (linked with 15.)	2/3
18.	Work	2
19.	Certainty about the future with respect to disease	2
20.	Expectations for the future	2
21.	Vitality, feeling alive	2
22.	Be able to take distance from one's situation, to place oneself outside the self	2
23.	No waiting list/good appointment system	2
24.	No financial problems	2
25.	(No) limitations, e.g., food	1

Note: The facets are rank ordered in terms of importance.

With the first facet listed in Table 3, "having peace or being in balance", the focus group members meant having accepted the limitations of a disease; being a stable person. The term 'work' consists of aspects such as distraction from someone's disease, social contacts and the financial aspect. With respect to work, the difference between what one wants to do and what one is able to do is sometimes a great source of frustration. Self-confidence means knowing that one can or cannot do certain things. Physical self-confidence refers to the situation that the functioning of the body can deteriorate which raises doubt or distrust about one's own body. With belief is meant philosophy of life. Belief was viewed as giving a meaning to life and events. Also mentioned was a need for rituals as a way of providing some kind of certainty. Finances were considered to be important in the sense that necessary things - having to use a taxi and having to pay someone who runs one's household or cleans one's house - can be a financial burden if one has to pay it using own financial resources.

According to the participants, age is an important factor. Children and the elderly (might) like being dependent on others. Having to cope with losses such as death of family members in a relatively short period of time is another aspect that plays an important role in QoL.

The facets numbered 10 to 13 all have to do with the health-care system and the medical profession. A conclusion that can be drawn from this is that a lack of social skills in doctors and caregivers could also influence the QoL of patients.

With regard to mobility (No. 6), it was said that lacking mobility frustrates one's initiatives. Powerlessness was also suggested in this context. Other aspects mentioned were a mental blockage causing people to lack the capacity to do anything; bad eyes; acceptance of the own illness or the illness of a significant other; the lack of an ability to relax; feelings of being a full-fledged person; the wish to do as much as possible in a short period of time out of fear that in a couple of years one will no longer be able to do these things anymore. Moreover, two participants mentioned the composition of food. Finally, it was said that the speed of doing things gradually becomes slower.

Regarding the question whether disease also has a positive side, several facets were mentioned such as the stimulation of inventiveness, the fact that one learns to see things from a different perspective, the fact that one can be happy with small things, the adjustment of norms and values, and the experience of really learning to know your friends.

The procedure followed in Group 2 was identical to the one in Group 1. The results are shown in Table 4.

Self-confidence (No. 9) was linked to work/activity (No. 3) in a more general sense of the word. Another phrasing used in this context was "being productive". Self-confidence also had to do with continuing to fight for one's own interest. Self-image (No. 10) had to do with one's function in life or one's place in society at a certain time. The function and place change and with it the self-

image.

Table 4. Facets of QoL; Group 2

No.	Facets	Importance rating
1.	Meaning of life	3
2.	Social contacts including family, friends, and acquaintances	3
3.	Work/activity (e.g., hobby); being active or productive	3
4.	Being self-supportive	3
5.	No pain (physical)	3
6.	Tie with family, friends	3
7.	Communication possibilities such as a telephone; an absence of communication problems	3
8.	Mobility; going where one wants to go	3
9.	Self-confidence	3
10.	Self-image	3
11.	No guilt (parents), e.g., about having a handicapped child	3
12.	Attention, not personal but for the problems diseases bring along (e.g., active through research)	3
13.	Positive emotions such as well-being, feeling comfortable, satisfaction	2/3
14.	Health	2/3
15.	Recreation/relaxation	2/3
16.	Having influence, e.g., on one's life	2/3
17.	No uncertainty about the course of illness and possibilities to realize plans	2/3
18.	Having good memories from the time one was not ill	2/3
19.	Understanding	2/3
20.	To do what one wants to do	2
21.	Natural environment such as house	2
22.	Public facilities	2
23.	Technical facilities	2
24.	Help from others to stay independent	2
25.	Money	2
26.	Not being rebellious; acceptance	2
27.	Distance (literally) from family, friends	2
28.	Sexuality (satisfying)	2
29.	Negative emotions called "mental pain", anger, anxiety, impotence, and frustration about what one cannot do anymore	2
30.	No shame	2
31.	Religion	1/2/3
32.	Being no public "possession"	1/2
33.	Visibility, this can be positive and negative	

Note: The facets are rank ordered in terms of importance. 1=Not very important; 3=Very important.

Most of the participants said that they plan only a (very) brief period of time ahead, such as one day or one week. The reason mentioned was that they did not know what would be possible after that period, for instance, due to pain.

Body image, food, and acceptance were also mentioned. When, for instance, persons have difficulty with speech, people they encounter (sometimes) think they are mentally retarded.

As a positive aspect they named the fact that one is inclined to appreciate small things in life more than in the period before the disease.

In both groups positive emotions were mentioned separately from negative emotions. According to the number of facets that reflect (different) feelings, emotions seem to play a major role in QoL.

The lists of facets generated by the participants overlap for a very large part with the list of facets as described in the Report of the first Meeting on Quality of Life at WHO (World Health Organization, 1992a). In addition, there is an overlap with the results from a study by Burckhardt, Woods, Schultz, and Ziebarth (1989). They asked four groups of persons with chronic illnesses (osteoarthritis (OA), diabetes mellitus, ostomy secondary to colon cancer or colitis, and RA) to describe areas that were important to their QoL. It appeared that, in general, all four groups used similar terms. The dominant themes mentioned included independence, being physically active, having the ability to care for self, being healthy, having a sense of security, positive interactions and relationships with others, and meaning in life. The participants with OA also emphasized freedom from pain, while those with diabetes emphasized being in control.

Areas that the participants in Group 1 felt were important to QoL but at the same difficult to talk about were: emotions, self-confidence, social contacts, sexuality (depending on the age of the respondent), and beliefs. In Group 2, these topics were (in)continence, sexuality, starting sexual relationships, and religion.

Generally, it was felt that all the facets could (easily) be asked about in a questionnaire. Furthermore, it was felt that it would be more difficult to talk about these facets in an interview situation.

3.4 Across centres

Similar preliminary focus groups were held in all other field centres with the exception of Zimbabwe. This country joined the WHOQOL study after this phase. On the basis of the information that came from all discussion groups, it appeared that the provisional list of domains and facets was largely confirmed. However, several revisions were suggested. In the end the following changes were made. The facets 'Eating/food and water supply', 'Sexual relationships', 'Employment status', 'Educational opportunity', and 'Costs of obtaining care' were dropped.

A number of facets were changed either in terms of the label and/or in terms of the content. The facet 'Sexual function' was relabelled into 'Sexual activity'. The facet 'Bodily movement (excluding mobility)' was changed into 'Motor functioning'. 'Walking and mobility' became 'Mobility'. 'Cognitive functioning' was renamed 'Thinking, learning, memory, and concentration'. 'Happiness and contentment' became the new name for 'Positive affect/happiness'. The facet 'Negative affect/emotional distress' was divided into two separate facets: namely 'Depression' and 'Anxiety'. 'Hopefulness' became 'Hopefulness and optimism'. The facet 'Self-efficacy/self-esteem/ability to

plan' was transformed into the two facets 'Self-esteem' and 'Self-efficacy'. Finally, 'Freedom, physical safety, and security' was substituted by 'Physical safety and security'.

Table 5. The new QoL structure

Domain I		Bodily states and functions
a)		Bodily states
	1.	Pain and discomfort
	2.	Vitality and Fatigue
b)		Bodily functions
	3.	Sexual activity
	4.	Sleep
	5.	Motor functioning
	6.	Mobility
	7.	Sensory functions
Domain II		Psychological functions
a)		Cognitive functions
	8.	Thinking, learning, memory and concentration
b)		Emotional functions
	9.	Happiness and contentment
	10.	Depression
	11.	Anxiety
	12.	Hopefulness and optimism
c)		Self concept
	13.	Self-esteem
	14.	Self-efficacy
	15.	Bodily image
Domain III		Levels of independence
	16.	Ability to carry out activities of daily living
	17.	Dependence on substances
	18.	Communication capacity
	19.	Working capacity
	20.	Participation in and opportunity for recreation and pastimes
Domain IV		Social relationships
	21.	Isolation/social contact
	22.	Family support
	23.	Support from friends/acquaintances
	24.	Activities as provider/supporter
	25.	Religion
Domain V		Environment
	26.	Freedom, physical safety and security
	27.	Quality of home environment
	28.	Quality of work environment
	29.	Work satisfaction
	30.	Opportunities for acquiring information and skills
	31.	Financial status
	32.	Availability to and quality of health and social care
	33.	Transport

In addition, a number of facets were added: 'Religion', 'Work satisfaction', 'Opportunities for acquiring information and skills', 'Availability to and quality of health and social care', and 'Transport'. The new QoL structure is shown in Table 5.

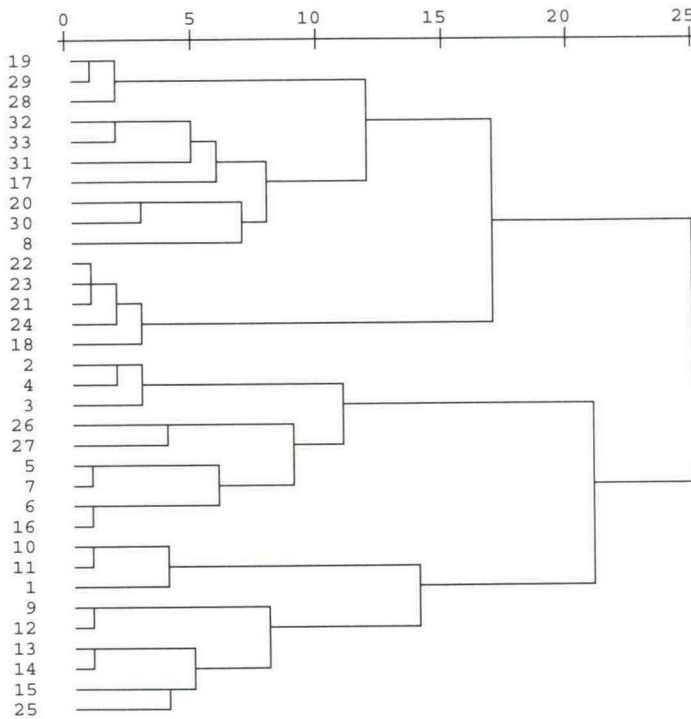


Figure 1. Dendrogram of the cluster analysis (Ward Method) of the pile sort task

The work with free-listing of important aspects of QoL had suggested that *health* was important to lay conceptions of QoL, although specific aspects of health/illness were not free-listed (WHO, 1992b). The reason that health was not listed by the experts (provisional structure of QoL) and only mentioned in general by the participants might be that health is so fundamental that it was taken for granted.

3.5 Face validity of the new QoL structure: Dutch data

After the new structure of QoL was developed, all facets were translated into Dutch using a forward-backward translation methodology developed by WHO (see Appendix III). Then, the members of the two preliminary focus groups ($N=10$) were contacted again. They were sent cards

with a facet printed on each of them. The cards were numbered on the backside in alphabetical order of the facet names. Thus, 'Ability to carry out activities of daily living' had number 1 and 'Working capacity' had number 33 (see Table 5 for the facet names). The assignment was to make piles of the facets. The facets they thought had something in common had to be placed together in a pile. They were allowed to make as many piles as they wanted. The instruction is listed in Appendix V.

Table 6. The four clusters resulting from the clusteranalysis

Cluster 1: Interaction with the environment

Availability to and quality of health and social care (Facet 32)
Transport (Facet 33)
Financial status (Facet 31)
Dependence on substances (Facet 17)
Participation in and opportunity for recreation and pastimes (Facet 20)
Opportunities for acquiring information and skills (Facet 30)
Thinking, learning, memory, and concentration (Facet 8)
Working capacity (Facet 19)
Quality of work environment (Facet 28)
Work satisfaction (Facet 29)

Cluster 2: Social relationships

Family support (Facet 22)
Support from friends/acquaintances (Facet 23)
Isolation/Social contact (Facet 21)
Activities as provider/supporter (Facet 24)
Communication capacity (Facet 18)

Cluster 3: Physical aspects

Vitality and fatigue (Facet 2)
Sexual activity (Facet 3)
Sleep (Facet 4)
Motor functioning (Facet 5)
Sensory functions (Facet 7)
Mobility (Facet 6)
Ability to carry out activities of daily living (Facet 16)
Freedom, physical safety and security (Facet 26)
Quality of home environment (Facet 27)

Cluster 4: Emotional aspects

Depression (Facet 10)
Anxiety (Facet 11)
Pain and discomfort (Facet 1)
Happiness and contentment (Facet 9)
Hopefulness and optimism (Facet 12)
Self-esteem (Facet 13)
Self-efficacy (Facet 14)
Body image (Facet 15)
Religion (Facet 25)

Nine persons (six females and three males; the age range was 19-71 years) participated in this part of the study. The piles made by each participant were put in individual similarity matrices. The scoring was as follows: '1' for facets in the same piles and '0' for facets of other piles. The nine individual similarity matrices were compiled into one similarity matrix by counting the '1' scores of the individual matrices. The similarity matrix was then changed into a dissimilarity matrix. For instance, maximum similarity with the score 9 was changed into a 0 and vice versa. Using SPSS/PC+, a clusteranalysis (Ward Method) was done. The results are shown in Figure 1 (the vertical numbers correspond with the number of the facets).

The four-cluster solution was chosen because more clusters did not enhance the interpretation of the clusters obtained. The four clusters (see Table 6) were labeled 'Interaction with the environment', 'Social relationships', 'Physical aspects', and 'Emotional aspects'.

A comparison between Table 6 and the new QOL structure represented in Table 5 revealed a substantial similarity of structure. So, it is fair to say that the cluster analysis revealed a very close match with the domains as described in the Report of the Meeting on Quality of Life (WHO, 1992a). However, there were some differences.

Cluster 1 contained major parts of Domain 3 and Domain 5. Nine of the 13 facets that were in either domain were in this cluster. Three facets had shifted to Cluster 3 (Physical aspects): namely Facet 16 (Ability to carry out activities of daily living), Facet 26 (Freedom, physical safety and security), and Facet 27 (Quality of home environment). Facet 18 (Communication capacity) was placed in cluster 2.

Cluster 2 (Social relationships) consisted of Domain 4 without Religion, but with Communication capacity (Facet 18).

With the exception of Facet 1 (Pain and discomfort), Cluster 3 equals Domain 1. This cluster was completed with the Facets 16, 26, and 27.

Finally, Cluster 4 contained Domain 2. However, instead of Facet 8 (Thinking, learning, memory and concentration), Facet 25 (Religion) and Facet 1 (Pain and discomfort) were in this cluster.

In general, both groupings of the facets were reasonably similar. Therefore, it can be decided that the domains as formulated in the Report of the Meeting on Quality of Life (WHO, 1992b) could be maintained. Taking the new structure of QOL, the next phase of the project could be started: running focus group to further validate the structure of QoL and generating questions for the instrument.

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CHAPTER 4 Focus groups

4.1 Aim of the focus groups

As already mentioned in the previous chapter, the general aim of the next phase in the development of the WHOQOL was to generate items. It was decided (WHO, 1992) that this would be done by conducting focus groups. To work with focus groups is a relatively new technique in psychology. Focus groups have their origins in sociology, although nearly all current applications are in market research (Morgan, 1988). Several studies suggest that focus groups form a reliable method to gather information (e.g., Stewart & Shamdasani, 1990; Van Assema, De Vries, & Kok, 1992).

A focus group is a type of *group interview* to generate ideas about a particular issue. Focus groups can be broadly defined as a technique whereby 4 to 12 individuals discuss a particular topic of interest under the direction of a moderator (*cf.* Stewart & Shamdasani, 1990). According to Morgan (1988), focus groups are useful for (i) orienting oneself to a new field, (ii) generating hypotheses based on informants' insights, (iii) evaluating different research sites or studying populations, (iv) developing interview schedules and questionnaires, and (v) getting participants' interpretations of results from earlier studies.

Unlike ordinary group interviews, in focus groups the reliance is on the interaction between the various participants. The primary role of the moderator is to promote interaction, probe for details when warranted, and ensure that the discussion remains directed toward the issue at hand (Stewart & Shamdasani, 1990). The role of the moderator can vary on a dimension ranging from completely in control to predominantly facilitating. Compared with participant observation, the main advantage focus groups offer is the opportunity to observe a large amount of interaction on a particular topic in a limited period of time (Morgan, 1988). Compared with individual interviews, one advantage of group interviewing is that the dynamic interplay of participants replaces their interaction with the interviewer, leading to a greater emphasis on the participants' points of view. Another supposed advantage is that they are much cheaper than individual interviews. However, this depends, of course, on the particular study. A more clear-cut advantage is related to the amount of time involved. The same number of participants can be interviewed in much less time using a group format. Moreover, there is a further savings in analysis time because fewer transcripts are required (Morgan, 1988).

Morgan (1988) has described the strengths and weaknesses of focus groups. The strengths are:

(i) focus groups are comparatively easy to conduct, while in many circumstances, the research can be done relatively cheaply and quickly, (ii) focus groups can explore topics and generate hypotheses, and (iii) the opportunity to collect data from group interaction. The weaknesses are: (i) focus groups are not situated in natural settings, (ii) the researcher has less control over the data gathering, and (iii) it is unclear whether or not the obtained information covers individual behavior.

The most obvious constraint on interview content is the typical length of a session, that is, between one and two hours. Within this time span, it is important to maintain the focus. It should be avoided to explore too many topics (Morgan, 1988). In the present project it was decided that the length of each focus group would be three hours¹.

Morgan (1988) and Van Assema *et al.* (1992) have recommended that the size of a focus group should be between 4 and 12 persons. However, the usual conclusion is to use "moderate sized" groups, which is somewhere between 6 and 10 (Morgan, 1988). In a group of less than four persons, the participants would not have any period in which they could withdraw themselves from the discussion. On top of this it was anticipated that it would be more difficult to get diverse points of view or ideas in a smaller group. Stated otherwise, the advantage of a group interview would disappear. On the other hand, a group of more than 12 persons is almost impossible to control by the moderator. First, there is the possibility of "social loafing", that is, each individual participates less because the group as a whole can carry the discussion. Second, larger groups have practical problems of their own. The more participants, the more difficult it is to manage their discussion. Third, discussions in large groups can break up into small conversations among neighbors around the table, which implies a loss of data because such conversations are very difficult to tape (Morgan, 1988).

The purpose of the present focus groups was threefold: (i) to generate items/questions for the WHOQOL, as already mentioned above; (ii) to check on the existing facet structure to see whether the full range of relevant topics was covered, which is essential for examining face validity (Fitzpatrick *et al.*, 1992); and (iii) to obtain importance ratings of facets. Due to these purposes, it was decided that the number of participants for each focus group was 6 to 8 persons. However, each field centre was allowed to broaden this range.

In each country, at least six focus groups had to be conducted; two focus groups for each of the

¹ There were three reasons for this. First, it is difficult for people to concentrate for a long time on a particular subject. When, however, a group session lasts three hours then there is some time for coffee breaks. Second, it could certainly not be any shorter because of the number of facets that had to be discussed. Third, it would be more difficult to recruit persons for two or more separate sessions.

following three kinds of group: (i) acute or chronically ill persons; (ii) people from the general population, including informal caregivers; and (iii) professional health care personnel. This wide range of backgrounds may enhance the process of establishing the face validity of the QoL structure (Fitzpatrick *et al.*, 1992).

4.2 Method

4.2.1 Subjects

In the Dutch study, the maximum number of participants in a focus group was nine persons. The six focus groups were conducted between December 7 and December 16, 1992. All meetings were held at Tilburg University. Each group was conducted by the same focus group moderator and assistant focus group moderator. The main tasks of the assistant moderator were to write the ideas of the participants on a flipchart and to take care of the tape recordings. Permission to put the whole discussion on tape was asked at the beginning of each meeting. All participants gave their consent.

There were two groups that consisted of *acute and chronically ill persons* (Focus Groups 1 and 3). The participants for these two groups were recruited through a letter to 19 patient organizations.

Focus Group 1 consisted of persons representing the following patient organizations: (1) Epilepsy, (2) Food allergy, (3) Head, heart and coronaries, (4) Hodgkin's disease, (5) Lupus Erythematoses, (6) Migraine, (7) Multiple Sclerosis, (8) Parkinson, and (9) Psoriasis.

Focus Group 3 would consist of people representing the following organizations: (1) Crohn and Colitis Ulcerosa, (2) Disabled persons, (3) Kidney disease, (4) Liver disease, (5) Rheumatoid arthritis, (6) People with a stoma, and (7) Sjögren's disease. However, three persons cancelled at short notice because of urgent matters concerning their work. These three persons were interviewed individually at a later date. Thus, this group consisted of four participants.

Two organizations, the Dutch Diabetes Organization and the Asthma Patient Organization, were not able to send a representative to one of the focus groups. Instead, they agreed to give their ideas and comments in writing. Only the Diabetes Organization of the Netherlands actually did so.

The composition of the groups, according to age, sex, and education, is shown in Table 1. Among the participants of the ill persons focus groups there were no persons with ages between 16 and 24 years. Furthermore, there were no males in the low education level category. This was to be expected because of the recruitment procedure and the focus of the groups. It was the intention to get persons into the focus groups who could talk out of personal experience as well as

knowledge stemming from contacts with fellow-sufferers. As was expected, these persons were somewhat older and had a higher education level. Here, the fact that chronic illnesses usually emerge after the age of 40 also plays a role.

Table 1. Participants of the focus groups

Demographic data	Ill groups	General population groups
Sex:		
Male	7	6
Female	8	9
Age:		
16-24	0	2
25-44	2	4
45-64	11	6
65+	2	3
Educational level:		
Low	1	2
Middel	2	5
High	11	8

Two other focus groups consisted of people from the *general population* (Focus Groups 2 and 4). They were recruited through an advertisement in a door-to-door spread local newspaper. People were asked to call if they were interested. Sixteen persons reacted, of which one person thought the advertisement called for people who were willing to fill out a questionnaire. He did not want to participate in thinking about the content of a questionnaire. The other 15 persons actually participated. There were nine persons in Focus Group 2 and six in Focus Group 4.

Sixty per cent of the participants were females, compared with 50.6 per cent in the general population (see Table 2). Thus, both sexes were reasonably well represented in the focus groups. Forty-seven per cent of the women between 15 and 65 years of age in the Netherlands have a middle or high education level. In the case of men, 56 per cent is educated at a middle or high level. Of the participants of the two focus groups 89 per cent of the women had an education level that was middle or high, compared with 83 per cent of the men. So, people with a low education level were underrepresented in these focus groups. Concerning the age of women, the focus groups gave a reasonably good picture. In the case of men, one age group was not represented, namely 16-24 years of age. Furthermore, men between 45 and 64 years of age were overrepresented (see Table 2).

The last two focus groups (Focus Groups 5 and 6) consisted of *health care workers*.² Only the person who worked at the National Organization Victim Aid was approached in the same way as the participants of the ill persons focus groups. This organization was explicitly asked to participate because of the special group of people they work with: people with traumas caused by abuse and traffic accidents. The professions of the health care workers were selected to represent a variety of different perspectives. The selected professions were: psychologists working in primary health care, psychotherapists, a nurse working at a psychiatric ward and a group worker. From the physical health care general practitioners, internists, nurses, and personnel working in home care were selected. If possible, each profession had to be represented in the two focus groups.

Table 2. Comparison of participants of the general population focus groups with the general population

Age	Females ¹	Females ²	Male ¹	Male ²
16-24	22.2%	17.8%	0%	19.3%
25-44	22.2%	37.3%	33.3%	40.5%
45-64	22.2%	26.1%	50%	27%
65+	22.2%	18.8%	16.7%	13.2%

¹ Persons from Focus Groups 2 and 4.

² General population of The Netherlands as per 1 January 1992 (CBS, 1993).

Table 3. Health care workers in the focus groups

Type of health care	Focus Group 5	Focus Group 6
Mental Health care	Psychologist in primary health care Psychotherapist Group worker	Nurse in PAAZ ¹
Physical Health care	General practitioner Internist Nurse Home care worker	General practitioner Nurse District nurse of Home care

¹ PAAZ stands for a psychiatric ward of a general hospital

² The participants, except one, were recruited by Mrs. J.F.M. Van Heck. She was given a list of professions that had to be represented in the two focus groups.

Table 3 shows the professions that were represented in both groups. Initially, persons with the desired professions were selected. However, not every one who had agreed to participate actually did. They cancelled the day before or on the day of the focus group meeting.

Focus Groups 3 and 6 only had four participants. Nonetheless, both focus groups were very informative, lively, and full of useful ideas. The low number of participants did not seem to have a negative effect on the information gathered.

4.2.2 Procedure

A document containing the facets and the facet definitions (see Appendix II) was sent to all the focus group participants one week before the meeting. This gave them the opportunity to read the document beforehand and to make notes about the facets if they wanted to.

When they arrived at the meeting they were first asked to perform a pile sorting task (Appendix V) identical to the one given to the participants of the preliminary focus groups (see Chapter 3). The purpose of this was twofold. First, to check the structure of quality of life. Second, to give them the opportunity to get acquainted with the facets. The participants were also asked to fill out a Demographic Questionnaire (Appendix VI) and an Importance Rating Questionnaire (Appendix VII).

After the pile sorting task and the administration of the Demographic Questionnaire, the participants introduced themselves to the group and the focus group moderator explained the purpose of the focus groups and their role in the present study.

The focus group moderator asked two questions with respect to each facet: (i) "How does <INSERT FACET> affect your quality of life?" and (ii) "How would you ask about <INSERT FACET>?". In the focus groups with health care personnel, the first question was slightly different. In that case, the first question was "How does <INSERT FACET> affect your patients' quality of life?".

The order in which the facets were discussed was not the same for each focus group. In the first focus group of ill persons, healthy lay persons, and health care personnel, the facets were presented in the order in which they are presented in the document with the definitions (see Appendix II), that is from Facet 1 (Pain and discomfort) to Facet 33 (Transport). In the second focus group of each kind, the facets were presented in the reversed order. Analogue to the focus groups, the order in which the facets were discussed in the individual interviews also differed. This was done to prevent any bias in the information collected. It appeared that the facets that were discussed at the beginning of a meeting took more time than the other facets.

Focus Group 1 only discussed the facets up to Number 16 (Ability to carry out activities of

daily living). Each facet took too much time. However, it was decided not to organize an extra focus group because of three reasons. First, the discussion about the facets that were discussed in Focus Group 1 showed considerable overlap with the discussion in Focus Group 3. Second, one member of Focus Group 1 was interviewed at home about the facets that were not discussed during the session of Focus Group 1. The content of this interview was fairly similar to the information collected in Focus Group 3. Third, there was not enough time to organize an additional focus group.

At the end of the meeting the participants were asked to fill out the Importance Rating Questionnaire (Appendix VII). After the participants finished the questionnaire, they were thanked for their participation and got a flower cheque of Fl. 15,- for the efforts they had made.

4.3 Dutch results

4.3.1 Generating items

The tape recordings made during the focus groups were used to make verbatim transcriptions of each focus group discussion and individual interview.

A question writing group was assembled consisting of three persons: the two principal investigators, of which one had been the focus group moderator, and the assistant focus group moderator. It was decided not to add a member of one of the focus groups to the question writing group for two reasons. First, this person would probably have biased the selection of the items. Second, the writing of the items would have taken considerably more time.

As mentioned in Chapter 2, the WHOQOL would have three levels of questions: perceived objective, self-reported subjective, and importance. The question writing group had to come up with at least one item for each level of questions for each facet.

The group was chaired by the focus group moderator. She read the verbatim transcripts of the focus groups and the individual interviews. All the members of the question writing group got a copy of the transcripts with possible useful questions marked by the chairperson. The question writing group scrutinized the complete material of one particular focus group before going to the transcript of another focus group. All questions that were thought to fit the three levels of questions needed were written down. This were not only questions suggested by members of the focus groups, but also items formulated by the question writing group using phrases in the transcripts as a starting-point. In this way, all the transcripts were screened very carefully for questions. The question writing group made sure that all facets had at least the required one item for each question level of each facet. If this was not the case, the group constructed an item. This

was also done on the basis of the transcripts. If there were more than three items for a particular level in a facet, the best three items were selected. For the items selected, see Appendix VIII.

4.3.2 Discussion

To give an indication of the nature of the discussions within the Dutch focus groups, here some core remarks are highlighted. For instance, with respect to the first facet, Pain and Discomfort, pain was seen predominantly as being connected with fear in the sense of fear of pain. According to many participants, pain can take control of one's life. Therefore, acceptance of pain was seen as very important. It was stressed that acceptance can contribute considerably to QoL.

Vitality (Facet 2; Vitality and Fatigue) was said to be vital for a good QoL. In discussing vitality, the participants made a distinction between tiredness due to, for example, sports, and tiredness as related to disease. The latter type of fatigue was seen as important to QoL in a negative sense.

Sexual Activity (Facet 3) appeared to be very difficult to talk about; especially for the older participants. Most participants said that sexual activity is not strictly necessary for a good QoL.

In contrast, Sleep (Facet 4) was stated to be important for a good functioning of a person. It was recognized that the necessary amount of sleep is a very personal affair which differs from person to person.

In some groups, Facet 5 (Motor functioning) was confused with Mobility. However, it was said that a deterioration of one's motor functioning causes dependence upon other persons. With respect to Mobility (Facet 6), people were predominantly talking about a lack of social contact due to a bad mobility. They also discussed transport in this context mentioning the dependence on others.

With regard to Sensory Functions (Facet 7), participants said that they were not capable of imagining what it would be like to lose one or more sensory functions. They thought that losing a sensory function would ruin their lives completely.

Thinking, Learning, Memory, and Concentration (Facet 8) were considered to be four very different functions that are difficult to combine in one facet. The participants mostly talked about memory and concentration. It was mentioned several times that these functions decline with age. This facet was also associated with pain; when a person is in pain, he/she is not able to concentrate. Consequently, this facet was considered to have a big impact on QoL.

With respect to Happiness and Contentment (Facet 9) a number of participants said that it is more or less equivalent to QoL. Contentment was conceived of as a too broad term; the question 'contentment with what?' was frequently asked.

There was some confusion about the facet Depression (Facet 10). It was not clear to the participants whether it meant a real clinical depression or just having the blues.

Anxiety (Facet 11) was mentioned in coercion with pain many times. Phobias were also mentioned. It was noted that it matters whether one has a realistic fear or not. It was stated that fear can completely control a person's life.

The facet Hopefulness and Optimism (Facet 12) was considered as the opposite of depression. Hope and optimism were seen as rather synonymous to QoL. It was also viewed as having to do with expectations about the future.

According to the participants, Self-esteem (Facet 13) was related to body and self-image. In addition, self-esteem was considered to be very important to QoL. However, the distinction between self-esteem and Self-efficacy (Facet 14) was not clear. When the latter facet was discussed, participants saw it as equivalent to self-confidence; they held the opinion that a person could not have self-esteem without self-efficacy and vice versa. Facet 15 (Body Image) was seen as having a possible influence on the two previous facets (Facets 13 and 14). A person's body image was considered as an important variable that has a great influence on QoL. It was also stressed that the social environment plays an important role in defining one's body image.

Concerning Facet 16 (Ability to Carry out Activities of Daily Living) the participants mentioned that the aspects 'acceptance' and 'being dependent on others' are of utmost importance.

With respect to Dependence on Substances (Facet 17), a distinction was made between dependence on medicine or alcohol or drugs. This difference was considered to be essential because a dependence on alcohol or drugs is a voluntary choice, which is often not the case regarding medication. The participants also pointed at the fear of not having substances within arm's reach.

Communication Capacity (Facet 18) was discussed as being very important for social contact. Without being capable of communicating a person was described as fully isolated.

In the case of the facet Working Capacity (Facet 19) the participants were predominantly focussing on paid employment. This facet was linked to satisfaction with work. Moreover, it was considered to be very much related to Facet 2 (Vitality and Fatigue).

Participation in and Opportunity for Recreation and Pastimes (Facet 20) was related to transportation, finances, and the availability of information. It was also related to social contact. The present facet was conceived of as important to QoL because of the fact that it reflects an ability to develop one's talents. Furthermore, it was seen as a way to express oneself.

Isolation/Social Contact (Facet 21) was thought of as the essence of QoL. It was made clear that

people can not do without social contact. However, it was recognized that sometimes people like to be alone. Moreover, a distinction was made between superficial and non-superficial contact. The first type of contact was not considered to represent *real* social contact.

Regarding Support from Family (Facet 22) the participants talked about the possibilities of getting unwanted support or too much help, which has a negative effect on QoL. However, on the whole, this facet was also considered as being essential for a good QoL. In this context, different kinds of support were discussed like financial and mental support. Many participants felt that this particular facet had a considerable overlap with Facet 23 (Support from Friends/Acquaintances). With respect to the latter facet a distinction was made between two kind of friends: real friends, who are always around when needed, and acquaintances. The participants pointed at the difficulty of asking for support. Also this facet was considered to be essential for people's QoL.

For the persons in the disease focus groups it was very difficult to see the point of view of support providers as reflected in Facet 24, Activities as Provider/Supporter. Nevertheless, it was thought that it could enhance the provider's sense of self-esteem because it might give him/her a good feeling.

Religion (Facet 25) was discussed as having a positive or a negative influence on a person's QoL. It was recognized that for some people religion can be a source of support. However, most participants were not religious.

Facet 26 (Freedom, Physical Safety, and Security) was thought of as being important for elderly people and women who might be afraid to go out in the evening. Freedom was considered to be important for people. When talking about physical safety, one often referred to various forms of abuse. It was agreed upon that this facet does not play a crucial role in Dutch society.

According to the participants, Quality of Home Environment (Facet 27) had to do with feelings of safety. The home has to be a safe place. With respect to Quality of Work Environment (Facet 28), social contact at work appeared to be very important. It was said that the work environment becomes especially important when one is not satisfied about the work itself.

The participants appeared to have the idea that Work Satisfaction (Facet 29) has influence on other parts of a person's life, for instance, on the individual's family.

Opportunities for Acquiring Information and Skills (Facet 30) was related to transport. The participants also talked about the fact that they found that nowadays there is an overload of information, which makes it difficult for persons to select the desired information.

About Financial Status (Facet 31), the participants were short. They said that it makes life very easy when one has money because that allows a person to do what he/she wants to do. Concerning Facet 32 (Availability of and Quality of Health and Social Care), the participants all agreed that

they were content with it; they rated the quality and availability of the care system as "good".

Finally, as already mentioned, Transport (Facet 33) was perceived as being entangled with a person's mobility. Participants made a distinction between public transport and personal transport. The difference between the facets Mobility and Transport was, according to many focus group members, not clear. The participants found the overlap between both facets enormous and therefore suggested to make one facet containing Mobility and Transport.

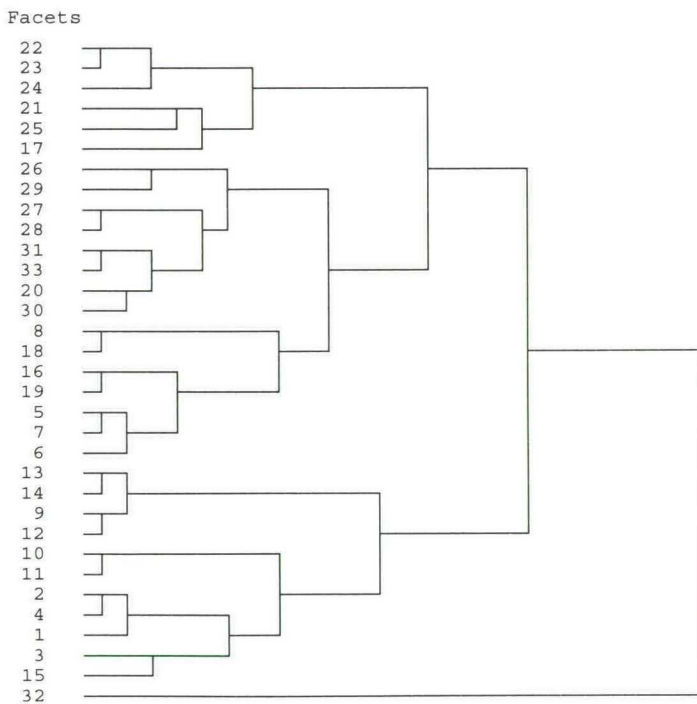


Figure 2. Dendrogram of all participants; Ward Method.

With a few exceptions, the validity and comprehensiveness of the facet list was considered as good. The exceptions had to do with the use of the term *substances* and with the perceived overlap between the facets Mobility and Transport. The Dutch equivalent of the word 'substances', "substanties", was not well understood by most members of the focus groups. The Dutch language does not contain an adequate alternative for the term 'substances'. Therefore, it was decided to include in the items an enumeration of the different kinds of substance (alcohol, tobacco, drugs, or medicine) instead of the summary label itself.

The face validity of the adapted QoL structure used in the WHOQOL project (Chapter 3, Table 5) was also checked by asking all participants to do a pile sorting task.

4.3.3 Face validity of the QoL structure

The participants got 33 cards with a facet printed on each of them. The cards were numbered on the backside in alphabetical order. The assignment was to make piles of the facets. The facets they thought had something in common had to be placed together in a pile. They were allowed to make as many piles as they wanted. The instruction is listed in Appendix V.

All 43 persons cooperated. The piles made by each participant were put in individual similarity matrices. The scoring was as follows: '1' for pairs of facets in the same piles and '0' for facets classified in different piles. The 43 individual matrices were compiled into one similarity matrix by counting the '1' scores of the individual matrices. The similarity matrix was then changed into a dissimilarity matrix. For instance, a maximum similarity with the score 43 was changed into a minimal dissimilarity of 0 and vice versa. Using SPSS/PC+, a cluster analysis was done. The results are shown in Figure 2.

The four-cluster solution was chosen because a solution with more clusters did not enhance the interpretation. The four clusters (see Table 4) were labeled as follows: Social Relationships; Interaction with the Environment; Self-reflection and Affectivity; and Health and Social Care.

A comparison between Table 4 and Table 5 from Chapter 3 shows an acceptable similarity in structure. It is fair to say that the cluster analysis revealed a fairly satisfactory match with the domains as described in the Report of the Meeting on Quality of Life (WHO, 1992). However, there were some differences. Cluster 1 (Social Relationships) consisted of Domain 4 plus Facet 17 (Dependence on Substances). Cluster 2 (Interaction with the Environment) contained Domain 5 without Facet 32 (Availability to and Quality of Health and Social Care) and Domain 3 without Facet 17 (Dependence on Substances). Furthermore, three facets from Domain 1 were grouped in this cluster: namely Facet 5 (Motor Functioning), Facet 6 (Mobility), and Facet 7 (Sensory Functions). Finally, Facet 8 (Thinking, Learning, Memory, and Concentration) of Domain 2 was classified in this cluster. Cluster 3 consisted of Domain 2 without Facet 8 (Thinking, Learning, Memory, and Concentration) which went to Cluster 2. Finally, Cluster 4 contained only one facet: Facet 32 (Availability to and Quality of Health and Social Care). This facet comes from Domain 5.

Table 4. The four clusters resulting from the cluster analysis of all participants

Cluster 1: Social Relationships

Family Support (Facet 22)
 Support from Friends/Acquaintances (Facet 23)
 Activities as Provider/Supporter (Facet 24)
 Isolation/Social Contact (Facet 21)
 Religion (Facet 25)
 Dependence on Substances (Facet 17)

Cluster 2: Interaction with the Environment

Freedom, Physical Safety and Security (Facet 26)
 Work Satisfaction (Facet 29)
 Quality of Home Environment (Facet 27)
 Quality of Work Environment (Facet 28)
 Financial Status (Facet 31)
 Transport (Facet 33)
 Participation in and Opportunity for Recreation and Pastimes (Facet 20)
 Opportunities for Acquiring Information and Skills (Facet 30)
 Thinking, Learning, Memory, and Concentration (Facet 8)
 Communication Capacity (Facet 18)
 Ability to Carry out Activities of Daily Living (Facet 16)
 Working Capacity (Facet 19)
 Motor Functioning (Facet 5)
 Sensory Functions (Facet 7)
 Mobility (Facet 6)

Cluster 3: Self-reflection and Affectivity

Self-esteem (Facet 13)
 Self-efficacy (Facet 14)
 Happiness and Contentment (Facet 9)
 Hopefulness and Optimism (Facet 12)
 Depression (Facet 10)
 Anxiety (Facet 11)
 Vitality and Fatigue (Facet 2)
 Sleep (Facet 4)
 Pain and Discomfort (Facet 1)
 Sexual Activity (Facet 3)
 Body Image (Facet 15)

Cluster 4: Health and Social Care

Availability to and Quality of Health and Social Care (Facet 32)

Now that the pile sort task has demonstrated that the face validity of the structure of QoL used in this project is reasonably good, the importance ratings for the 33 facets of QoL were studied.

4.3.4 Importance ratings

The participants were asked to indicate the importance of each facet in order to see whether any facet was judged by nearly everyone as unimportant. If this would be the case that facet could be removed from the facet list. The participants of the healthy and the ill persons focus groups were

asked to fill out the Importance Ratings Questionnaire concerning themselves. The professional health care personnel also filled out the questionnaire with the difference that they were asked to answer the questions for their patients. The response scale was a five-point scale (Appendix IX), ranging from 1 (*Most important*) to 5 (*Not important*).

Before looking at the importance ratings for the facets, it was checked whether there were any differences between the various kinds of focus groups. For this purpose, one-way analyses of variance were run for each facet. Only the facets Depression and Anxiety revealed significant differences ($p = 0.0029$ and $p = 0.0256$, respectively). In both cases the professional health care workers had scored the facets Depression and Anxiety as more important to their patients' QoL than the ill and healthy persons did with respect to their own lives. It appeared that the professional health care workers thought that both facets were *Most important* or *Very important* to their patients' QoL (90.9% and 100%, respectively). Nearly 44 percent (43.8%) of the ill persons had scored Depression as *Most important* or *Very important*. In the case of the healthy persons, this percentage was slightly more than 50 per cent (53.8%). Anxiety was scored as *Most important* or *Very important* by 50 per cent of the ill persons and 38.5 per cent of the well participants.

Because there appeared to be little difference between the three types of focus groups concerning their opinion about the importance of facets, the importance ratings were scrutinized in order to investigate whether a facet could be removed from the list because of the fact that it was judged to be unimportant. This appeared not to be the case. There were 14 facets on which one or more participants (the maximum was 6) had scored the facet as *Not important*. On two of these facets, Facet 17 (Dependence on Substances) and Facet 25 (Religion), 14% of all participants scored *Not important*. The participants of all kinds of focus group judged most facets as *Somewhat important*, *Very important*, or *Most important*. There were 16 facets where at least 75% judged them as *Most important* or *Very important*. There were even four facets (Facet 7, Sensory Functions; Facet 8, Thinking, Learning, Memory, and Concentration; Facet 18, Communication Capacity; and Facet 21, Isolation/Social Contact) where 90% or more of the participants scored *Very important* or *Most important*.

A report containing this information as well as the results from the pile sort task, the generated items, and the core of the content of the different discussions was sent to WHO.

4.4 Across centres³

Each of the other field centres also wrote a report on the focus group work and sent it to WHO where all the reports were analyzed with respect to the suggestions made concerning the facet structure, the proposed questions for the WHOQOL, and the importance ratings. The suggestions relating to the facet structure will now be discussed in conjunction with the importance ratings. The process from proposed questions written by each centre to the pilot instrument will be one of the topics in the next chapter.

The focus group discussions and the importance ratings of the facets gave rise to a number of issues concerning the relationship between facets. In light of all the focus group reports a few changes were made to the facet structure that will be discussed by domain. That means that since no adaptations were made to Domain I (Physical domain), first changes within facets of the Psychological domain will be mentioned followed by changes in the Level of Independence domain, etcetera. However, a newly added facet will be discussed first.

The current focus group work reinforced the earlier finding in the preliminary focus groups (Chapter 3) with respect to health. The focus group participants again validated the broad concept of health as crucial to people's perception of their overall QoL. They did so without making direct reference to specific facets such as pain or sleep. The broad conception of health appeared to include the prospect of ill health and disability. Therefore, it was decided that this broader perception of QoL and health should be included in the WHOQOL as a facet under the name *Overall Quality of Life and Health*. It was felt that this new facet fell outside the existing domain structure because it requires a respondent to give a global evaluation of his/her QoL and health. Upon request, questions for this facet were written by the questions writing panels in each of the centres.

Several changes were made in the Psychological domain. The facet concerned with happiness and contentment was felt to be too narrow in focus. It missed the many positive feelings that people felt contributed to their QoL. For this reason, a broader more comprehensive facet entitled *Positive Feelings* replaced it. Subsequently, this new facet could also subsume the former facet 'Hopefulness and Optimism'. It is worth noting that many focus group participants indicated that it was difficult to distinguish it from QoL itself, thus emphasizing its primacy in the facet structure (This was supported by data from Bath, Harare, Melbourne, Seattle, Tilburg, and Zagreb).

With respect to the two facets Depression and Anxiety, a number of centres had noted in their report that these facets were judged to be too psychiatric in their definitions. In addition, the more

³ This section is based on the report on the focus group work (WHO, 1993).

'normal' and relatively common negative feelings such as having the blues were excluded in the discussions, although they nonetheless would influence QoL. In order to overcome these difficulties, the facets Depression and Anxiety were merged into a new facet named *Negative Feelings*. This collation of the negative affect facets had the additional benefit of avoiding any ambiguity about the severity of the negative feeling which is sometimes implied by the words *anxiety* and *depression*. Another aspect that arose from the focus group reports in relation to negative affect had to do with mental suffering due to pain. The participants frequently reported that the facet (Pain and Discomfort) only covered physical suffering but not mental suffering. The facet Negative Feelings would be better able to incorporate mental suffering due to physical pain than the two previously suggested facets focusing on depression and anxiety.

Thus, the new facet structure includes the two facets Positive Feelings and Negative Feelings. The reason for the inclusion of these two facets, instead of making one facet that covered the whole range of affects (from negative to positive), is that in a number of previous studies (e.g., Bradburn, 1969; Watson, Clark, & Carey, 1988; Watson, Clark, & Tellegen, 1988) it emerged that positive and negative affect might be two related but different dimensions. The independence of these two facets would later be confirmed in the pilot work where, for instance, in the Dutch study the correlation between Positive and Negative Feelings was -0.54.

The concept Self-esteem was seen as a broad ranging concept that is closely related to and difficult to distinguish from self-efficacy (e.g., Tilburg). In addition, reports of the focus group work in many of the field centres suggested that self-esteem is conceived of differently in Western and Eastern cultures. The individual perspective was conceived of as central in the Western conceptions of self-esteem. In contrast, in both Eastern and African cultures the collective perspective of externally judged esteem of the family or peer group was more important. To incorporate this cultural variation in the understanding of the facet concerned with perception of self, the facet definition of Self-esteem was broadened. Another point raised by some centres was that they felt that the self-esteem facet was more meaningful to individuals who were more used to and comfortable with introspection.

With respect to the facet Body Image, which is an aspect of self-esteem, no recommendations were made to incorporate it in the self-esteem facet. However, although no remarks were made concerning Body Image, this facet was redefined into *Body Image and Appearance*. The scope of the body image facet was broadened to include someone's perception of his/her appearance. Up to now it included only the more culture-specific conception of body image.

Almost every centre indicated that focus group participants had found two facets of the domain Level of Independence, Motor Functioning and Mobility, difficult to distinguish. This was either

on conceptual grounds or with regard to their effects on QoL. In addition, a number of centres reported that some focus group participants had difficulty understanding what was meant by motor functioning. It appeared that only those relatively few individuals with impairments in the motor function area would be able to relate fully to questions about body movements. Thus, only the facet Mobility was retained, and the facet concerned with motor functioning was omitted in the revised facet structure. The omission of motor functioning as a distinct WHOQOL facet by no means indicated that this facet is not felt to be important. The descriptive reports of the focus group discussions as well as the importance ratings of the facet suggested that motor functioning was considered an important issue that potentially might affect QoL detrimentally. However, it was felt that other facets (e.g., Mobility, Activities of Daily Living, etc.) would adequately cover the effects that impairments in motor functioning would have on a person's QoL as defined in this project.

Concerning the facet Dependence on Substances, many centres commented that the fact that this facet included both dependence on medicinal substances/procedures (e.g., insulin or a pacemaker) and dependence on illegal drugs (e.g., heroin)/non-medicinal substances (e.g., alcohol) was very confusing (e.g., Tilburg). Therefore, it was decided to split Dependence on Substances into two facets: *Dependence on Medicinal Substances/Medical Aids* and *Dependence on Non-medicinal Substances (e.g., alcohol, tobacco, caffeine)*. An additional advantage of this division into two facets was that it subsequently allowed a more detailed exploration of the effects of medication and treatments on QoL in general, and in particular the effects of life saving medication (e.g., insulin) on QoL.

Considerable overlap between the facets in the Social Relationships domain was noted in a number of centres. In particular the distinction between support from family and friends appeared to be unnecessary, particularly given the cultural differences in the populations included in the phase of WHOQOL work. For example, in the United States, focus group participants tended to ask what was meant by family. It appeared that some participants had a somewhat different conception of family. For instance, a number of persons regarded their network of close friends as their 'family'. In cultures where the family unit is still central to a person's support network, the spouse and blood family were the primary source of support. As a focus group participant in England noted: "The real thing is, does the person have enough support? Where it comes from isn't important". As a result, the two facets Support from Family and Support from Friends/Acquaintances were merged into one facet called *Practical Social Support*.

Remarks or comments concerned with other facets of the Social Relationships domain also led to

changes within the facets. For instance, it emerged that focus group participants held the opinion that, because the field of intimacy and loving relationships is very important, it was inadequately covered in the facet structure. Based on their focus group work, the field centre in Zagreb remarked that it was felt important to reflect the opportunity for a good marital partnership in the assessment of QoL. This was judged to be different from, and not adequately covered by, the social support facet. In another centre, a good marital partnership was conceived of as 'non-sexual intimacy' which was not covered by the sexual activity facet. Therefore, a new facet entitled *Personal Relationships* was introduced.

It was noted in several reports that social isolation is a double edged sword. It is sometimes desirable and sometimes undesirable. Furthermore, focus group participants remarked that there are considerable individual differences in the level of social contact that people need or want. In light of the comments, the social isolation facet, which only dealt with social isolation, was dropped from the facet structure. The reason was that it is likely to be captured by the facets *Personal Relationships* and *Practical Social Support* because social isolation is a fundamental aspect of these facets. In other words, social isolation can have a negative effect on QoL precisely because it results in the person living without intimacy, love, and practical social support. Furthermore, questions that were related to the role of social isolation in social relationships were included in the global item pool, under the two facets *Personal Relationships* and *Practical Social Support*.

The facets *Work Satisfaction*, *Quality of the Work Environment* (both from the *Environment* domain), and *Work Capacity* (*Level of Independence* domain) appeared to bring up similar issues in focus group discussions. It was felt that a facet *Work Satisfaction* could adequately cover the two facets from the *Environment* domain and thus contain aspect of the quality of the work environment, the social climate at work, a person's satisfaction with the work that he/she does, and a person's suitability for the work. Therefore, they were combined into a single facet *Work Satisfaction*. *Work Capacity*, on the other hand, addressed an important and different aspect of QoL and was therefore retained as a separate facet.

The facet *Participation in and Opportunities for Recreation and Pastimes*, previously in the domain concerned with the person's level of independence, was moved to the domain concerned with the environment. This was done because it appeared to be not just the ability to enjoy leisure activities, but also the opportunity for, enjoyment of and relaxation derived from these activities that contributed to a person's QoL.

A number of field centres reported that some participants had noted the absence of a facet to cover broader perceptions of a person's environment in terms of pollution, climate, traffic congestion, and so on. Participants used terms like 'clean air' and 'less traffic', which were not

covered by any existing facet. For this reason, a facet named *Physical Environment (pollution/noise/traffic/climate)* was added.

The facet covering religion proved to be a problem in the focus group work. In the discussions it emerged that the participants felt it was important to only some persons. This was reflected in the rankings of means of the importance weightings. Several centres suggested to broaden the ground covered by the religion facet to include also spirituality and a person's personal beliefs. In this way the importance reflected in the focus group discussions, but not in the importance ratings, could be incorporated into the revised facet called *Spirituality/Religion/Personal Beliefs*. Like the global facet Overall Quality of Life and Health, this revised religion facet was seen as falling outside the domain structure. For this reason as well as the fact that it appeared to play an all encompassing aspect of life in some of the centres like Thailand, this facet was turned into a separate domain with the same label as the facet, namely *Spirituality/Religion/Personal Beliefs*.

The process of developing the pilot instrument and the final WHOQOL, the so-called Field Trial Version of the WHOQOL or WHOQOL-100, will be the topic of the next chapter.

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CHAPTER 5 Development of the WHOQOL-100 Field Trial Version

A number of steps were taken in developing the WHOQOL-100. After the focus group material was gathered this information was used to construct the pilot version of the WHOQOL. The process from focus group material to the so-called Field Trial Version of the WHOQOL or WHOQOL-100, will be described here. In addition, the characteristics of the Field Trial Version will be mentioned. Finally, the psychometric properties of the Dutch WHOQOL-100 will be scrutinized using the pilot data.

5.1 The pilot instrument

Making full use of focus group transcripts, a set of questions was derived for the pilot WHOQOL instrument. In addition, using visual analogue scales containing the anchor points of the rating scales on ten centimeter lines, culture-specific response scales were developed. Both the development of the questions and the response scales will be described in more detail in this chapter.

The pilot instrument was standardized in terms of format, instructions, core questions, and administration. It was administered in the period December 1993 to June 1994 to at least 250 ill persons and 50 healthy persons in each field centre. All centres together had 4,718 respondents who completed the pilot instrument.

5.1.1 Questions

In each centre the question writing panel framed a maximum of six questions for each facet at each of the two levels of questioning: perceived objective and self-report subjective. The drafting panels used criteria that were set to frame the questions (see Appendix X). The questions were drafted in all centres and were first written in the language of the particular field centre. They were then translated into English. The third type of questions, importance questions, were uniform across centres.

All the questions that had resulted from the focus group phase were sent to WHO, Geneva, by all the centres. There, all questions were combined into a large question pool, referred to as the 'global question pool', of some 1,800 questions. Subsequently, all questions were scrutinized once more by a working group¹, using the criteria set for question writing. Questions that did not meet

¹The working group or core instrument finalization group consisted of Dr Arroyo Sucre, Dr Bourkovski, Dr Caria, Dr Herrman, Mr Kitikorn Meesapaya, Dr Kuyken, Dr Mutambirwa, Dr Patrick, Dr Quemada, Dr Rajkumar, and Dr Rosser. Some of these persons only participated in this group for half a day or one day.

these criteria were removed from the question pool. A content analysis of the questions identified several semantically equivalent questions. For instance, "How much of the time are you tired?" and "How often are you tired?". These questions were clustered together. In this way the number of questions in the global question pool was reduced drastically. These judgments of *semantic equivalence* were made by consensual agreement in the working group and were subsequently reviewed by all the principal investigators. This procedure led to a considerable reduction in the number of questions in the global pool to about 1,000 questions.

Conceptual clustering of the questions within facets and within levels of questioning was carried out by the same working group. The assignment was to cluster those questions that inquire into the same aspects, the same end of a dimension, or the same direction of a facet. An example of each of the three types of conceptual clustering will be given. First, an example of a facet that might include several aspects requiring separate questions is Pain and Discomfort. This facet has the following aspects: intensity/frequency of pain, control of pain, distress caused by pain, and disability caused by pain. A facet that requires questions addressing both ends of a particular dimension is Energy and Fatigue; the two end-points being energy/vitality and tiredness/exhaustion. Finally, the facet Sexual Activity has positively framed questions like "How satisfied are you with your sex life?" and negatively framed questions such as "Do you have sexual problems?".

Subsequently, the question pool was sent back to all the centers, where the conceptual clusters and the questions were rank-ordered for each facet in terms of how much each revealed about a respondent's QoL in the particular culture. The goal of this exercise was to select the clusters and the perceived objective and the self-reported subjective questions for the final question pool and the pilot questionnaire. The conceptual cluster were ranked *within facets*, separately for different types of questions. Then, the questions were rank-ordered *within conceptual clusters*. In the Netherlands, the ranking exercise was done individually by three persons, all psychologists. Then, average rank orders per cluster were calculated. Subsequently, the conceptual cluster with the lowest mean received rank number 1, the cluster with the next lowest mean rank number 2, etcetera. The same procedure was followed in the case of the questions.

When two or more mean rankings of clusters or questions within a facet were equal, then the range of these clusters or questions were compared. The conceptual cluster or question with the smallest range received the lowest rank number of the clusters or questions concerned. In the case where the mean ranking as well as the range of the conceptual clusters or questions within a facet were equal, the lowest appropriate rank number with the questions was first given to a group of identical questions when possible. When this all failed, the remaining clusters and questions were discussed and ranked on the basis of this discussion. A similar procedure was followed in all the

centres.

From the combined rankings for all centres, 236 questions were selected for the pilot version of the WHOQOL. This 236-item question pool is presented in Appendix X. In selecting questions, the conceptual clusters were useful in ensuring that all important aspects of each facet were represented in the pilot instrument.

Although some facets of QoL are universal across cultures (e.g., Mobility), others such as Self-esteem, Personal Relationships, and Spirituality/Religion/Personal Beliefs, differ from one culture to another. The ranking by all centres may favor more global questions. As a consequence important, but culture-specific, features of facets may have been omitted. Several field centres have chosen to include a number of culture-specific questions in their national version of the pilot WHOQOL instrument. For example, in Thailand, where the vast majority of the population are Buddhists, the national version of the instrument included the following questions for the facet Negative Feelings: "How well are you able to rid yourself of negative feelings through meditation?". This question would clearly be inappropriate for most respondents in other settings, but addresses an important aspect of psychological well-being in Thailand. Such questions are additions to the agreed-upon core questions, and, as already mentioned in Chapter 2, will have to compete with the 'global' questions in the analysis of the pilot data (WHOQOL group, 1994). In the Dutch pilot WHOQOL instrument no national/regional questions were added. Tilburg contributed 50 (21%)² of the core questions.

The pilot instrument contained 236 core questions (perceived objective and self-reported subjective) covering 29 facets of QoL within six domains and one global facet. In some centres, a limited number of national/regional questions were added. In addition, 41 importance questions were included in the pilot WHOQOL as well. These items were also developed on the basis of the focus group reports. From these reports it emerged that the importance questions were identical in all centres. Furthermore, the importance questions had the same format for all facets: "How important to you is?".

At the same time of the development of the items for the pilot instrument, the response scales had to be made. A special procedure was used for the development of the intermittent points of the four five-point response scales concerned with Intensity (*Not at all - Extremely/An extreme amount*), Capacity (*Not at all - Completely*), Frequency (*Never - Always*), and Evaluation (*Very satisfied - Very dissatisfied; Very good - Very poor*).

² This does not mean that these 50 questions were only contributed by Tilburg. Some of the questions were also suggested by one or more of the other centres.

5.1.2 Response scales

This procedure ensured, first, that response scales were not simply translated from a source language, with all the problems associated with such a procedure. Second, it secured a high degree of scalar equivalence among languages, which was supported by subsequent bilingual review. Third, it ensured equidistance between descriptors on the scales. Of course, in line with the views of commentators (Dressler, Viteri, Chavez, Greli, & Dos Santos, 1991; Reise, Widaman, & Pugh, 1993), further formal testing of the dimensional equivalence of these scales in the different cultures is needed. This is planned as part of the WHOQOL's field testing.

Ensuring equivalence in response scales requires a methodology that goes beyond translation of standardized English-language scale descriptors. Although endpoints such as *Never* and *Always* are more or less universal, shades of meaning *between* endpoints (e.g., *Sometimes*) are more ambiguous, difficult to translate, and subject to cultural variation with respect to interpretation.

To ensure equivalence across WHOQOL field centres, a procedure was used that specified the anchor points for each of the four types of five-point response scales and a metric scale on which intermediate descriptors could be plotted. This procedure involved several steps, the first being the translation of the standardized anchor points. Then, for each response scale, a list of at least 15 descriptors indicating intermediate positions was compiled - from dictionaries, a thesaurus, relevant literature, and a perusal of other questionnaires - in the language of the field centre. Subsequently, for each response scale, 20 lay subjects with different educational backgrounds (low to high), age, and sex were asked to mark the points on a 100-mm visual analogue scale where they thought each descriptor had to be placed in relation to the two anchors. The series of descriptors for a given response scale were presented in random order, and a new line was used for each descriptor. Three intermediate descriptors were selected from the means falling within the following ranges: 20 mm-30 mm, 45 mm-55 mm, and 70 mm-80 mm. If several descriptors fell within a given range, the descriptor with the lowest standard deviation was selected. To check on the ordinality of response scales, a small sample of lay respondents was asked to rank-order the descriptors for each response scale in a card sort exercise. To check on the comparability of the derived descriptors among centres, a bilingual review process was used.

5.1.3 Instructions for completing the questionnaire

In the questionnaire instructions, the way in which a respondent had to respond was explained. In addition, whenever a new response scale was introduced, there was a heading at the top of the page in which the response scale was explained. In principle, all questions were ordered by type of response scale. However, the questions of the facets concerning work (Work Capacity and Satis-

faction with Work), Mobility, and Spirituality/Religion/Personal Beliefs were the only ones grouped together. The reason was that they had a special heading explaining the respondents the content of the facet. For instance, the facets about work had to be interpreted as meaning all types of major activities including cleaning one's house and not merely a paid job outside the house.

5.1.4 Testing the pilot WHOQOL instrument³

Subjects

For this pilot phase, all centres were asked to try to get at least 250 ill persons and 50 well persons. In addition, half of the respondents had to be younger than 45 years of age and gender had to be representative for the various illnesses. A wide range of diseases with mixed severity had to be included.

In total 4718 respondents filled out the pilot instrument. The global mean age was 43.5 years (range 37.7 for Bangkok to 48.2 for Tilburg). In general, 53.2 percent of all the respondents were female, ranging from 44.0 percent in Beer Sheva to 62.9 percent in Tilburg. Finally, 80.9 percent of the respondents was sick (range 69.0%, Melbourne - 83.6%, Barcelona).

Selection of questions

As already mentioned in paragraph 5.1.1, the pilot instrument consisted of three types of questions. The selection of the questions for the Field Trial Version of the WHOQOL only concerned the perceived objective and the self-report subjective questions. In order to establish whether a distinction between these two types should be retained in the selection of the questions, correlations between them were calculated for each of the 30 facets. The correlations between the perceived objective and the self-report subjective questions appeared to range from 0.26 for the facet Activities as Provider/Supporter to 0.90 for Work Satisfaction. Because, on average, the correlation between the two types of questions was 0.71, the distinction between them was dropped and all questions - except the importance questions - were taken together.

First, items with more than 20 percent of missing data were excluded⁴. Then, the selection of the

³ The data and analyses described in this paragraph are based on the work done by Prof. dr. M. Power (member of the Data Analysis Group) as represented in the report concerning the meeting of the WHOQOL group in Montreal in October 1995 (MNH/PSF/96.1).

⁴ There were also instructions for the persons entering the data in the computer about how to act when a respondent had circled more than one answer. If a respondent had circled two answers, there were two ways to handle this. First, the highest of the two responses had to be selected. Second, to alternate the higher and lower responses in a predetermined order, for instance, LHLHL, etcetera. When a respondent had circled three answers, the middle one should be entered. Finally, if the respondent had circled more than three answers, this had to be treated as missing data.

questions for the Field Trial Version started. The procedure for this selection consisted of three steps.

In Step 1, items were removed when there was either a *frequency* problem, a *reliability* problem, or a *mapping* problem. A *frequency problem* existed when there was a distribution problem in more than eight centres. The criterion used to identify a distribution problem was that (i) less than 10% of the respondents had chosen two consecutive rating points and/or (ii) there was a problem in the global analysis, i.e., in the combined data set consisting of all the data from all centres ($N > 4000$). Thirty-eight questions were dropped because there was a frequency problem. Four questions showed a frequency as well as a reliability problem. A *reliability problem* existed when the corrected item-facet correlation was less than 0.40 in eight or more centres and in the combined data set. Seven items were removed because they showed such a problem. Finally, a *mapping problem* occurred when items correlated higher than 0.40 with facets other than their own facet. This appeared to be the case with six items. In addition, one question had a frequency and a mapping problem and was therefore dropped.

In Step 2, the data from each centre were scrutinized to identify the questions which showed a non-significant item-total (facet) correlation for that particular item. This was the case for 11 items. An item with a non-significant item-total correlation was only removed when: (i) in more than one centre this problem existed, which happened in the case of two items; (ii) such an item was also a problem at Step 1, which was the case for one item; or (iii) there was also a problem at Step 3, which occurred three times.

In Step 3, the sick and the well respondents were compared at the global data level, that is, across all field centres. There were 23 items for which the distinction between the two groups of respondents was not significant. However, these items were only eliminated when they also were problematic in Step 1 or 2, which happened with eight questions.

Subsequently, facet-domain correlations were calculated. Then, based on the three steps and the facet-domain correlations, a number of facets were deleted. The facet Sensory Functions was dropped because of a low facet-domain correlation and Dependence on Non-Medical Substances (e.g., alcohol, tobacco, drugs) because of huge frequency problems (Step 1) with facet items; only one item did not have a frequency problem. Communication Capacity was dropped for two reasons. First, because all items except two had either a frequency or a reliability problem (Step 1). Second, because of a low facet-domain correlation. Another facet that did not stay in the new WHOQOL structure was Activities as Provider/Supporter. The reason was the extent of frequency and reliability problems. The only item without psychometrical problems could be moved to the facet Personal Relationships, where it showed a high item-total correlation. Satisfaction with Work

was the last facet that was removed. It failed to distinguish sick from well persons.

Finally, the items for the Field Trial Version were selected from the remaining questions. For each facet the four items with the highest item-total correlation were selected. However, some exceptions were made, for instance, when items within the 'top 4' had too much overlap with one another. Thus, if question *X* ranked 3 in terms of item-total correlation, but correlated very high ($r > 0.40$) with question *Z* which ranked 1, then question *X* was removed and replaced by the item with rank 5. The reason for taking four items for each facet was twofold. First, it is easier to score a questionnaire with a uniform structure. Second, if there are less than four items this will present problems for analyses in relation to new centres.

Table 1. Questions that were removed after the initial selection and their replacements

Items that were removed

- F 0 How is your health?
- F 2 How satisfied are you with the energy you have to do what you need to do?
- F 5 How satisfied are you with your memory?
- F 9 How much difficulty do you have getting around by yourself?
- F15 How satisfied are you with the sexual aspects of your life?
- F22 How noisy is the area in which you live?
- F24 How much does religion have a positive influence on your life?

Items that replaced the removed ones

- F 0 How would you rate your quality of life?
 - F 2 How much are you bothered by fatigue?
 - F 5 How would you rate your memory?
 - F 9 How well are you able to get around?
 - F15 Are you bothered by any difficulties in your sex life?
 - F22 How concerned are you with the noise in the area you live in?
 - F24 To what extent do you feel your life to be meaningful?
-

After the questions for the Field Trial Version were chosen based on empirical data, the Data Analysis Group⁵ went over these questions and proposed a small number of changes based on theoretical grounds. These theoretical grounds were either that not all aspects of a facet were represented in the new questionnaire or that there was only one type of question, perceived objective or self-report subjective, selected. Although the distinction between the two types of questions had disappeared on empirical grounds, it emerged that the vast majority of facets contained both types of questions. Therefore, it was decided to try to have both perceived objective or self-report subjective in all facets. However, items were only replaced if the psychometric properties of the

⁵ The Data Analysis Group consisted of the following persons (in alphabetical order): Dr. M. Bullinger, Dr. W. Kuyken (WHO), Dr. J. Orley (WHO), Prof. dr. D. Patrick (Seattle), Prof. dr. M. Power (Edinburg), and Prof. dr. G.L. Van Heck (Tilburg).

newly selected items was reasonably good. Based on these criteria, in seven facets one question was replaced by another. These facets were Overall QoL and General Health, Energy and Fatigue, Thinking, Learning, Memory, and Concentration, Mobility, Sexual Activity, Physical Environment (pollution/noise/traffic/climate), and Spirituality/Religion/Personal Beliefs. The question F0 that was dropped from the global facet items was moved to the demographical questions. The seven items that were changed are shown in Table 1.

Using correlations, it appeared that *all* domains were significantly related to the global facet Overall QoL and General Health. Furthermore, when the facet Positive Feelings was entered first in a multiple regression analysis, the other facets all contributed significantly to the prediction of the global facet. Thus, QoL as measured in the WHOQOL is more than just a reflection of 'positive feelings'.

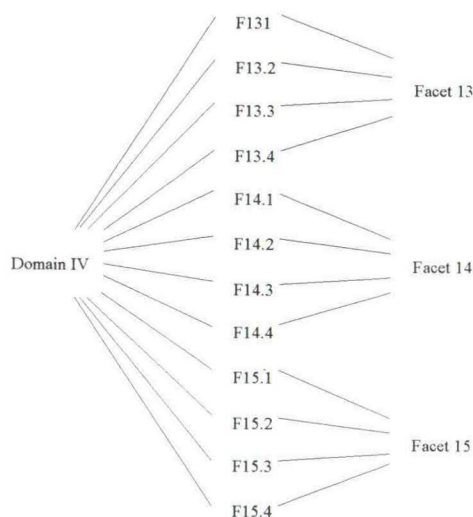


Figure 1. Schematic structure of the WHOQOL-100⁶

In order to test the structure of the WHOQOL, structural equation modelling (EQS program) was used. A series of increasingly complex models were tested. First, a single factor model was tested which appeared to have a poor fit. Second, a two-factor model with the domain Environment as a separate factor was investigated. The fit of this model was also poor. The third model,

⁶ The author would like to thank the Data Analysis Group for their work.

had two factors; the first factor consisted of all six domains and the second factor consisted of the domains II to VI. Thus, Domain I, Physical Health was excluded. This model had a good estimated fit (CFI=0.995; $\chi^2=57.4$) and is represented in Figure 1; the fit of that model was good. The analyses suggest that two factors are needed for a domain-overall QoL score. However, the second factor in the third model (without Domain I) is conceptually difficult to understand, because in the current QoL literature, the physical dimension is considered as a fundamental element. In addition, it would become difficult to realize the anticipated uses of the instrument when a physical domain is lacking. For this reason, another model was tested in which the first factor again contained all six domains, but the second factor contained the domains I to IV and VI, leaving out Domain V (Environment). This model appears to fit the data just as well.

Table 2. Summary of rank of item-facet correlations for national questions

	Rank in facet									
	1	2	3	4	5	6	7	8	9	10+
Total:	0	2	1	2	6	11	10	12	18	31

This means that domain scores are very useable and that the facet scores can be used for special purposes. That is, when domain scores are needed, they can be calculated by summing the item scores or by summing the facet scores. For a short form, this means that one or two items of each facet can be used to constitute domain scores.

National questions

Nine centres - Bath, Bangkok, New Delhi, Madras, St. Petersburg, Tokyo, Zagreb, Harare, and Beer Sheva - had included national items in the pilot instrument. For instance, Bangkok (Thailand) added 25, Bath (UK) and Harare (Zimbabwe) 4, and St. Petersburg (Russia) 27 questions. However, these national items did not perform better than the global items did. A summary of ranks of inter-facet correlations for the national questions is given in Table 2. An example is presented in Table 3 (the items in bold were national items). Thus, there are no national items added to or in the WHOQOL-100 in any of the centres.

Table 3. An example of item-facet correlations of national items: facet Self-esteem (the national items are in bold)

	Global	Madras
How much do you value yourself?	0.61	0.58
How do you feel about yourself?	0.67	0.51
How much confidence do you have in yourself?	0.65	0.56
Do you regard yourself as worthy of respect from others?	0.42	0.47
How satisfied are you with yourself?	0.67	0.55
How satisfied are you with your abilities?	0.63	0.62
How satisfied are you with the respect you get from others?	0.48	0.56

Importance questions

The importance questions suggest whether or not facets can be removed because, in general, they are conceived of as not important to people's lives. When looking at the mean importance scores, it became apparent that the WHOQOL did not contain any redundant facet. Concerning the importance questions, scored on five-point scales, it appeared that the range of means in the global dataset (i.e., across all centres) was narrow: 3.29 for the facet Sexual Activity to 4.29 for Activities of Daily Living. When looking at the data for each centre separately, it emerged that the lowest average importance score was 2.60 in Tokyo for Sexual Activity.

In addition, it appeared that the most important facets are the more basic functions such as activities of daily living, energy, health, and sensory functions. The least important facets in nearly all centres were Sexual Activity and Body Image and Appearance.

5.2 The WHOQOL-100

5.2.1 Characteristics of the instrument

Structure of the WHOQOL-100

The current instrument consists of 100 items assessing Overall QoL and General Health and 24 other facets of QoL. The WHOQOL-100⁷ is the same in each centre, i.e., not only structure wise but also at the item level. The questions that are in the Field Trial Version appear to be *universal* in the sense that they came out of the analyses as the best questions in all centres.

⁷ The Dutch version of the WHOQOL-100 is presented in Appendix XI

Each facet is represented by four items. Initially, a distinction was made between *perceived objective* and *self-report subjective* questions. However, because these two types of questions appeared to be highly correlated, as already mentioned above, this distinction was not retained in the sense that scores can be calculated separately for both types of questions.

Each question must be answered on 5-point Likert type scales. No changes have been made to the response scales.

Table 4. Structure of the WHOQOL-100

Overall Quality of Life and General Health	
<u>Domain I:</u>	<u>Physical Health</u>
*	Pain and Discomfort
*	Energy and Fatigue
*	Sleep and Rest
<u>Domain II:</u>	<u>Psychological Health</u>
*	Positive Feelings
*	Thinking, Learning, Memory, and Concentration
*	Self-Esteem
*	Body Image and Appearance
*	Negative Feelings
<u>Domain III:</u>	<u>Level of Independence</u>
*	Mobility
*	Activities of Daily Living
*	Dependence on Medication or Treatments
*	Working Capacity
<u>Domain IV:</u>	<u>Social Relationships</u>
*	Personal Relationships
*	Social Support
*	Sexual Activity
<u>Domain V:</u>	<u>Environment</u>
*	Physical Safety and Security
*	Home Environment
*	Financial Resources
*	Health and Social Care: Availability and Quality
*	Ability to Acquire New Information and Skills
*	Participating in and Possibilities for Recreation/Leisure
*	Physical Environment (pollution/noise/traffic/climate)
*	Transport
<u>Domain VI:</u>	<u>Spirituality/Religion/Personal Beliefs</u>

The recognition of the multi-dimensional nature of QoL is reflected in the WHOQOL structure.

The WHOQOL is organized into six broad domains of QoL. These are: (i) Physical Health; (ii) Psychological Health; (iii) Level of Independence; (iv) Social Relationships; (v) Environment; and (vi) Spirituality / Religion / Personal Beliefs. Within each domain a series of facets of QoL summarize that particular domain of QoL. For example, the domain Physical Health includes the facets *Pain and Discomfort*, *Energy and Fatigue*, and *Sleep and Rest*. The second domain, Psychological Health, contains the facets *Positive Feelings*, *Thinking*, *Learning*, *Memory*, and *Concentration*, *Self-esteem*, *Body Image and Appearance*, and *Negative Feelings*. In Level of Independence, facets like *Mobility* and *Activities of Daily Living* are incorporated. The final structure of the WHOQOL-100 is depicted in Table 4. The WHOQOL's overall coverage of QoL ensures a conceptual coherence, or Gestalt.

From the global data analyses, the WHOQOL-100 seemed to have a good validity and reliability. For instance, in the global pool of data, the internal consistency (Cronbach alphas) for the facets ranged from 0.65 for Physical Environment (pollution/noise/traffic/climate) to 0.93 for Working Capacity. In addition, the questionnaire makes a distinction between healthy and chronically ill subjects. Furthermore, the WHOQOL-100 is also culture-specific for each centre involved in the development of the instrument in the sense that the concept, structure, and the questions were developed within each centre. Finally, the 100 items had good psychometric properties in all centres.

Scoring

The following guidelines are used. After reversing the scores on a number of items, facet scores can be calculated. This is done by taking the mean score of the four questions belonging to a particular facet, and multiplying this mean score by four⁸. Subsequently, these facet scores can be used to calculate domain scores. Before doing so, the scores on three facets - Pain and Discomfort, Negative Feelings, and Dependence on Medication or Treatments - have to be reversed. Then, domain scores can be calculated in the same way as was described for the facet scores. For instance, the scores on Energy and Fatigue, Sleep and Rest, and the reversed facet Pain and Discomfort are summed and divided by three. If one of the facet scores is missing, the mean of the remaining two facets is calculated and divided by three. In this way the possible range of scores on facets as well as domains is 4 to 20. With the exception of the three facets that have to be reversed, the higher one's score, the higher one's QoL concerning that particular facet or domain.

⁸If a respondent has not answered one of the four items, the mean score of the remaining three items will be calculated and multiplied by four. If a respondent does not answer two or more items of a facet, the facet score can not be computed.

Importance questions

In addition to the 100 items that now make up the so-called Field Trial Version of the WHOQOL, the importance questions ($n=32$) have been retained. However, the status of these importance questions is not clear. The importance questions will not be used for weighting facets because that will not provide useful information. The rationale is that the number of items for each facet is rather limited and only items with a high item-total correlation have been selected for the final instrument. In addition, the range of the responses on the importance questions was very small indicating that all facets were important. Furthermore, the importance of facets will have to be checked every time because one does not know how stable the importance ratings are over time. Finally, the importance ratings indicated that for the development of a short version of the WHOQOL one has to skip items and not facets, because all facets were considered important.

In the reliability and validity studies that will be done using the WHOQOL-100, the policy is to gather data concerning these importance questions, if possible. However, it is not obligatory.

5.2.2 Dutch results: psychometric properties

Subjects

In the Dutch centre, 417 persons participated in the pilot testing of the WHOQOL. From a wide range of patient organizations (19), ten⁹ agreed to cooperate. Each organization sent 50 letters from the university (and sometimes the patient organization) to its members with a request for participation in this study. These members were randomly selected from the membership lists, keeping in mind that the 50 persons had to be representative for the members of the particular organization with respect to socio-demographic factors such as age and sex. This was done, because patient characteristics, especially age, level of disability and cognitive function are very important in selecting a measure of health-related quality of life (Erickson & Scott, 1993).

From the 525 persons that received the request for cooperation 330 persons (62.9%) were sent a test-booklet which contained, among other things, the 277 items of the WHOQOL. From these 330 persons who all agreed to cooperate, 316 (95.8%) returned a completed test-booklet¹⁰. Nineteen

⁹ The participating patient organizations were involved with the following diseases: (i) Crohn's disease and colitis ulcerosa; (ii) diabetes; (iii) liver diseases; (iv) migraine; (v) chronic fatigue syndrome (CFS); (vi) psoriasis; (vii) Parkinson's disease; (viii) rheumatic diseases; and (ix) Sjögren's disease. In addition, an organization whose members had a stoma was also involved in this study.

¹⁰ The response rates for each patient organization were as follows: rheumatic diseases 86%; Parkinson's disease 70%; Crohn & colitis ulcerosa 54%; Sjögren's disease 54%; psoriasis 60%; CFS 95% (25 persons who were not asked to participate wanted a test-booklet, thus 75 CFS patients were sent a test-booklet of which 71 completed it); diabetes 32%; migraine 52%; stoma 54%; and liver 28%.

chronically ill persons were recruited through a more general approach discussed below. Thus, the total group of somatically ill consisted of 335 respondents. The age range in this group was 17 to 86 years ($M=49.7$; $SD=13.84$) and the majority (63.6%) were female. Furthermore, 175 persons (52.2%) were married. However, 20.9 percent had not answered the question about marital status. Concerning level of education, 75 (22.4%) had a low and 78 (23.3%) a high level; 22 (6.6%) did not answer this question. Finally, it appeared that approximately one-third (37.6%) had a paid job and 42.1 percent did not. One-fifth of the persons did not respond to this question.

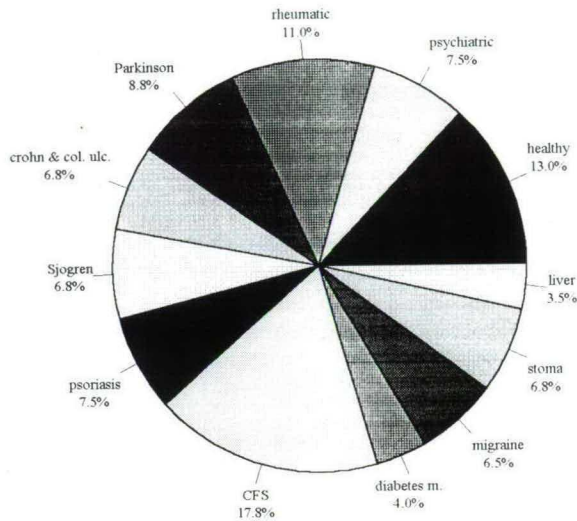


Figure 2. Distribution of respondents across diseases

General population. The response rate was 33.5 percent ($N=71$) of which 52 were healthy. Approximately one-third of these healthy persons was male and the youngest person in this group was 19 years old, whereas the oldest was 67 years of age ($M=45.5$; $SD=12.89$). More than half of the healthy persons (55.8%) was married. The marital status was missing for 11.5 percent (6 persons). While 7 persons (13.5%) only had a low educational level, 19 (36.5%) had a high education level. Two respondents did not answer this question. Paid work was done by 37 (71.2%) persons, while 12 (23.1%) subjects indicated not to have a paid job.

In order to recruit psychiatric patients as well, a colleague¹¹ from the University of Amsterdam gave 50 test-booklets to outpatients from the psychiatric department of the academic hospital. From these 50 persons, 60 percent ($N=30$) returned a completed WHOQOL. Half of the psychiatric res-

¹¹I would like to thank Drs Chijs Nieuwenhuizen for collecting the data among psychiatric outpatients.

pondents were females. The youngest person was 21 and the oldest 64 ($M=37$; $SD=9.88$). The average number of years that a person had received education was more than 14 years ($M=14.4$; $SD=4.67$; range 3 - 20). Finally, only 30 percent was living with a partner. The distribution of diseases among the total group of respondents is shown in Figure 2.

Reliability

In order to investigate the internal consistency of the various facets and domains of the WHOQOL-100, Cronbach's alphas were calculated.

Table 5. Internal consistency of the WHOQOL-100 facets and domains

WHOQOL-100 scales	Cronbach's alpha
Overall Quality of Life and General Health	0.87
Domain I: Physical Health	0.75
Pain and Discomfort	0.75
Energy and Fatigue	0.93
Sleep and Rest	0.92
Domain II: Psychological Health	0.81
Positive Feelings	0.83
Thinking, Learning, Memory, and Concentration	0.80
Self-Esteem	0.84
Body Image and Appearance	0.87
Negative Feelings	0.86
Domain III: Level of Independence	0.84
Mobility	0.93
Activities of Daily Living	0.91
Dependence on Medication or Treatments	0.87
Working Capacity	0.94
Domain IV: Social Relationships	0.72
Personal Relationships	0.73
Social Support	0.85
Sexual Activity	0.85
Domain V: Environment	0.83
Physical Safety and Security	0.74
Home Environment	0.82
Financial Resources	0.90
Health and Social Care: Availability and Quality	0.80
Opportunities for Acquiring New Information and Skills	0.77
Participation in and Opportunities for Recreation/Leisure	0.78
Physical Environment (pollution/noise/traffic/climate)	0.71
Transport	0.86
Domain VI: Spirituality/Religion/Personal Beliefs	0.85

As is shown in Table 5, the reliability of the WHOQOL-100 appeared to be good. For the facets

the internal consistency ranged from 0.71 for Physical Environment (pollution/noise/traffic/climate) to 0.94 for Working Capacity. With regard to the domains the coefficients ranged from 0.72 (Social Relationships) to 0.85 (Spirituality/Religion/Personal Beliefs).

Content validity

Subsequently, the correlations between the domains were calculated. In general, it appeared that the domains were related to one another, but none of them appeared to be redundant. With the exception of Domain VI (Spirituality/Religion/Personal Beliefs), all domains were significantly correlated with each other. Among Domains I to V the correlations ranged from 0.39 ($p < 0.001$) for Domain III with Domain IV to 0.76 ($p < 0.001$) for Domain I with Domain III. Concerning Domain VI, it emerged that this domain was not related to the Domains I and III (see Table 6).

Table 6. Correlations between the domains

	Domain II	Domain III	Domain IV	Domain V	Domain VI
Domain I	0.55***	0.76***	0.46***	0.55***	0.06
Domain II		0.48***	0.66***	0.59***	0.32***
Domain III			0.39***	0.54***	0.03
Domain IV				0.60***	0.26***
Domain V					0.15**

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

When the correlations between facets and domains were calculated, it appeared that all facets correlated highest with its own domain. In addition, the global facet Overall Quality of Life and General Health correlated, in general, between 0.64 (Social Relationships and Environment) and 0.71 (Psychological Health) with the domains. An exception was Spirituality/Religion/Personal Beliefs for which $r = 0.26$ ($p < 0.001$) was found.

However, to exclude the confounding effect between facets and their domains (of which facets constitute a part), new domain scores were calculated. For domain scores facets belonging to that domain were not included one at a time. For instance, in the case of Domain I three new domain scores were calculated: one without Facet 1, one without Facet 2, and one without Facet 3. These three new scores as well as the other domain scores (in this case Domain II to Domain VI) were correlated with Facet 1, Facet 2, and Facet 3. This was done for all domains except Domain VI, because this domain only contains one facet. Subsequently, item-rest correlations were calculated.

From the item-rest correlations, it appeared that Facet 1 (Pain and Discomfort) and Facet 2

(Energy and Fatigue) were both correlated higher with Domain III (Level of Independence) than with its own domain. In addition, Facet 3 (Sleep and Rest) was related highest to its own domain (see Table 7).

The Facets 4 (Positive Feelings), 6 (Self-esteem), 7 (Body Image and Appearance), and 8 (Negative Feelings) had the strongest relationships with the domain it belongs to, that is, Domain II. Facet 5 (Thinking, Learning, Memory, and Concentration) correlated higher with Domain V (Environment) than with the own domain (Domain II: Psychological Health) (see Table 7).

Concerning the facets belonging to Domain III (Level of Independence), it appeared that all these facets correlated highest with their own domain (see Table 7).

Both Facet 13 (Personal Relationships) and Facet 15 (Sexual Activities) correlated higher with Domain II (Psychological Health) than Domain IV (Social Relationships). Otherwise, the facets belonging to Domain IV correlated highest with their own domain (see Table 7).

Table 7. Correlations concerning the facets of Domain I corrected for confounding effects

	Domain I	Domain II	Domain III	Domain IV	Domain V	Domain VI
Facet 1	-0.60	-0.42	-0.62	-0.33	-0.42	-0.04 ^{ns}
Facet 2	0.63	0.50	0.76	0.45	0.50	0.05 ^{ns}
Facet 3	0.53	0.42	0.48	0.36	0.42	0.06 ^{ns}
Facet 4	0.44	0.68	0.40	0.62	0.55	0.39
Facet 5	0.50	0.51	0.49	0.49	0.51	0.17
Facet 6	0.32	0.72	0.29	0.54	0.40	0.36
Facet 7	0.27	0.48	0.23	0.39	0.32	0.17
Facet 8	-0.53	-0.64	-0.37	-0.50	-0.49	-0.18
Facet 9	0.62	0.37	0.76	0.32	0.53	0.00 ^{ns}
Facet 10	0.77	0.51	0.80	0.43	0.60	0.03 ^{ns}
Facet 11	-0.37	-0.18	-0.42	-0.13 ^{**}	-0.13 ^{**}	-0.01 ^{ns}
Facet 12	0.75	0.52	0.76	0.44	0.54	0.08 ^{ns}
Facet 13	0.45	0.71	0.40	0.69	0.59	0.29
Facet 14	0.35	0.47	0.27	0.51	0.48	0.28
Facet 15	0.34	0.44	0.31	0.42	0.37	0.06 ^{ns}
Facet 16	0.32	0.47	0.25	0.42	0.55	0.18
Facet 17	0.35	0.43	0.29	0.47	0.65	0.17 ^{**}
Facet 18	0.29	0.31	0.30	0.34	0.52	0.03 ^{ns}
Facet 19	0.45	0.31	0.44	0.36	0.57	-0.02 ^{ns}
Facet 20	0.43	0.52	0.50	0.45	0.59	0.22
Facet 21	0.47	0.62	0.45	0.59	0.53	0.29
Facet 22	0.26	0.23	0.20	0.29	0.49	0.01 ^{ns}
Facet 23	0.40	0.31	0.48	0.31	0.55	-0.04 ^{ns}

Note: With exception of the correlations marked with ** ($p < 0.01$) and ^{ns} (not significant), the correlations are significant at $p < 0.001$ level.

Facet 21 (Participation in and Opportunities for Recreation/Leisure) was the only facet of Domain V (Environment) that was correlated higher with another domain than its own. It correlated 0.62 with Domain II (Psychological Health) and 0.59 with Domain IV (Social Relationships) (see Table 7).

Subsequently, two stepwise regression analyses were executed with the global facet Overall Quality of Life and General Health as the dependent variable. From the first analysis, it appeared that *all* six domains significantly predicted the score on the global facet (adjusted $R^2=0.71$; $F=167.74$, $p<0.001$). In the second analysis, the facet Positive Feelings was entered first, followed by the domains. It emerged that Domain V (Environment) no longer significantly predicted the global facet score (adjusted $R^2=0.73$; $F=183.56$, $p<0.001$).

Acceptability

Read, Quinn, and Hoefer (1987) mentioned that time required for administration, requirements for special training or equipment, the mode of administration, and acceptability to subjects and interviewers are important aspects, when evaluating measures. Therefore, these four aspects will be discussed for the WHOQOL-100.

First, the WHOQOL-100 is a self-report measure; the respondents answer the questions without the assistance of an interviewer. Because of this, there is no need for a special training of an interviewer or special equipment. To complete the questionnaire takes approximately 15 to 20 minutes. Finally, acceptability of a measure can be studied by looking at the amount of missing data. At the domain level, the percentages of missing data were 0.2 percent for the domains I (Physical Health), IV (Social Relationships), and V (Environment), 0.7 percent for Domain II (Psychological Health), and 1.2 percent for the domains III (Level of Independence) and VI (Spirituality/Religion/Personal Beliefs) (see Table 8).

Looking closer at the percentage of missing data, it emerged that especially Facet 19 (Health and Social Care: Availability and Quality) has a high percentage of missing data (5.5%). This leads to the conclusion that, in general, the acceptability of the WHOQOL-100 appeared to be good. The facet labeled 'Health and Social Care: Availability and Quality' seemed to be an exception. This co-incided with the fact that with respect to this particular facet a number of respondents placed the remarks "not applicable" or "I don't know" besides the questions.

Floor and ceiling effects

Another important aspect in the evaluation of the questionnaire is the distribution of the answers, because this gives an indication about possible floor and ceiling effects. There is a floor effect if

many respondents select the lowest response possible. In a ceiling effect most respondents are located at the top end of the response scale.

Table 8. Missing data and floor and ceiling effects of the WHOQOL-100 for the total group

Domains and facets of the WHOQOL-100	Frequency of missing data (%)	Actual lowest and highest scores ¹	Kurtosis	Skewness
Overall QoL & General Health	7 (1.7)	4 - 20	-0.39	-0.28
Domain I	1 (0.2)	5.67 - 20.00	-0.84	-0.03
Pain and Discomfort	3 (0.7)	4 - 19	-0.48	-0.03
Energy and Fatigue	1 (0.2)	4 - 20	-1.03	0.03
Sleep and Rest	2 (0.5)	4 - 20	-0.88	-0.29
Domain II	3 (0.7)	7.80 - 19.20	-0.10	-0.40
Positive Feelings	2 (0.5)	5 - 20	0.15	-0.48
Thinking, Learning, Memory, and Concentration	3 (0.7)	5 - 20	-0.29	-0.33
Self-esteem	3 (0.7)	5 - 20	0.20	-0.27
Body Image and Appearance	2 (0.5)	4 - 20	0.18	-0.81
Negative Feelings	4 (1.0)	4 - 20	-0.50	0.22
Domain III	5 (1.2)	5.25 - 20.00	-0.97	-0.03
Mobility	3 (0.7)	5 - 20	-1.22	-0.12
Activities of Daily Living	4 (1.0)	4 - 20	-0.90	-0.23
Dependence on Medication or Treatments	4 (1.0)	4 - 20	-1.03	-0.06
Working Capacity	12 (2.9)	4 - 20	-0.97	-0.13
Domain IV	1 (0.2)	4.67 - 20.00	0.02	-0.32
Personal Relationships	1 (0.2)	5 - 20	-0.07	-0.53
Social Support	6 (1.4)	4 - 20	-0.36	-0.23
Sexual Activity	14 (3.4)	4 - 20	-0.49	-0.15
Domain V	1 (0.2)	7.38 - 20.00	0.20	-0.42
Physical Safety and Security	2 (0.5)	6 - 20	0.08	-0.36
Home Environment	1 (0.2)	6 - 20	0.04	-0.60
Financial Resources	4 (1.0)	4 - 20	0.06	-0.79
Health & Social Care: Availability Quality	23 (5.5)	4 - 20	1.11	-0.59
Ability to Acquire New Information & Skills	7 (1.7)	6 - 20	-0.39	-0.29
Participating in & Possibilities for Recreation /Leisure	3 (0.7)	5 - 20	-0.50	-0.37
Physical Environment (pollution/noise/traffic/climate)	1 (0.2)	6 - 20	0.08	-0.23
Transport	2 (0.5)	4 - 20	0.35	-0.89
Domain VI	5 (1.2)	4 - 20	-0.37	-0.18

Note: possible scores range from 4 to 20 for both domains and facets

As is shown in Table 8, the lowest and highest possible score on each facet and on the domains was usually present in the total group of respondents. However, there were only a few persons who were scoring at the low extreme (score=4) of the scales (maximum of 8.6%). At the high extreme

(score=20), the percentage of respondents was 20.1 percent in the case of Transport, 15.3 percent in the case of Mobility, and 11.5 percent in the case of Financial Resources. This could have been expected because in the Netherlands many persons have a car and there is a wide network of public transport. Concerning the other facets, the highest percentage of respondents that had a score of 20 was 9.1 for Sleep and Rest.

Patrick and Erickson (1993) stated that generic measures provide the basis for assessing ceiling effects because it may be difficult to detect positive changes when persons are already quite healthy; their initial scores are already high. In order to see how many respondents had a score of 4 or 20 at the facet and domain level, the lowest and highest WHOQOL-100 scores of the ill and the well persons were scrutinized separately (see Table 9).

It appeared that for the group of healthy respondents, no one had the lowest or highest possible score on the domains Physical Health, Psychological Health, Level of Independence, and Environment and the facets Pain and Discomfort, Positive Feelings, Self-Esteem, Negative Feelings, Health and Social Care: Availability and Quality, and Physical Environment (pollution /noise/traffic/climate). Furthermore, the lowest score was only present with respect to two facets: (i) Dependence on Medication or Treatments and (ii) Energy and Fatigue. In the latter case there was one person (1.4%) who obtained the score of 4, whereas this was true for 20 persons (28.2%) in the case of Dependence on Medication or Treatments. Concerning the maximum score of 20 at domain level, this happened only twice: on the domains Social Relationships and Spirituality/Religion/ Personal Beliefs. Each time it was only one person. At the facet level there were a number of facets where one or more persons had the maximum score of 20. However, in general this concerned less than 11 persons. Only with respect to two facets - Mobility and Transport - more than 20 percent of the healthy respondents had the maximum score (29.6% in both cases; see Table 9). Thus, in general it appeared that the WHOQOL-100 did not suffer from ceiling effects in well persons. The exceptions seemed to be the facets Mobility and Transport. An indication of a floor effect was present for the facet Dependence on Medication or Treatments.

With respect to the group of ill respondents, it appeared that for 14 facets and one domain there was at least one person who had the minimum score of 4. Concerning Domain VI there were five persons (1.4%) who had scored a 4. The facets with the highest percentage of respondents with the minimum score were Energy and Fatigue and Dependence on Medication or Treatments. However, in both cases this concerned only 16 persons (4.6%). With the exception of Pain and Discomfort, all facets had at least one respondent who had the maximum possible score (20). The two facets with the highest percentages of persons with the score 20, although still less than 20 percent - were the same as for the healthy group: Transport with 18.2 percent (63 persons) and Mobility with 12.4

percent (43 persons). At the domain level, each time one person (0.3%) scored 20 on the domains Physical Health, Level of Independence, and Environment, two persons (0.6%) had the maximum score for Domain IV, and the same goes for eight persons (2.3%) for Domain VI (see Table 9). It can be concluded that concerning the sick respondents, no floor or ceiling effects were found.

Table 9. Floor and ceiling effects of the WHOQOL-100 for healthy and sick persons separately

Domains and facets of the WHOQOL-100	Lowest and highest scores for the healthy group (freq.:%)	Lowest and highest scores for the ill group (freq.:%)
Overall QoL & General Health	5 - 20 (2; 2.8)	4 (4; 1.2) - 20 (8; 2.3)
Domain I Pain and Discomfort Energy and Fatigue Sleep and Rest	7.67 - 19.33 5 - 16 4 (1; 1.4) - 20 (2; 2.8) 5 - 20 (10; 14.1)	5.67 - 20.00 (1;0.3) 4 (3; 0.9) - 19 4 (16; 4.6) - 20 (5; 1.4) 4 (2; 0.6) - 20 (28; 8.1)
Domain II Positive Feelings Thinking, Learning, Memory, and Concentration Self-esteem Body Image and Appearance Negative Feelings	8.20 - 18.00 8 - 18 7 - 20 (1; 1.4) 7 - 19 7 - 20 (6; 8.5) 5 - 17	7.80 - 19.20 5 - 20 (1; 0.3) 5 - 20 (4; 1.2) 5 - 20 (7; 2.0) 4 (1; 0.3) - 20 (23; 6.6) 4 (10; 2.9) - 20 (1; 0.3)
Domain III Mobility Activities of Daily Living Dependence on Medication or Treatments Working Capacity	7.25 - 19.50 6 - 20 (21; 29.6) 8 - 20 (8; 11.3) 4 (20; 28.2) - 18 5 - 20 (3; 4.2)	5.25 - 20 (1; 0.3) 5 - 20 (43; 12.4) 4 (5; 1.4) - 20 (17; 4.9) 4 (16; 4.6) - 20 (8; 2.3) 4 (13; 3.8) - 20 (12; 3.5)
Domain IV Personal Relationships Social Support Sexual Activity	8.00 - 20.00 (1; 1.4) 8 - 20 (2; 2.8) 7 - 20 (3; 4.2) 7 - 20 (5; 7.0)	4.67 - 20 (2; 0.6) 5 - 20 (12; 3.5) 4 (2; 0.6) - 20 (19; 5.5) 4 (3; 0.9) - 20 (15; 3.5)
Domain V Physical Safety and Security Home Environment Financial Resources Health & Social Care: Availability & Quality Ability to Acquire New Information & Skills Participating in & Possibilities for Recreation/Leisure Physical Environment (pollution/noise/traffic/climate) Transport	11.13 - 17.75 10 - 20 (1; 1.4) 6 - 20 (2; 2.8) 7 - 20 (7; 9.9) 7 - 19 8 - 20 (2; 2.8) 6 - 20 (2; 2.8) 8 - 19 8 - 20 (21; 29.6)	7.38 - 20.00 (1; 0.3) 6 - 20 (10; 2.9) 6 - 20 (22; 6.4) 4 (3; 0.9) - 20 (41; 11.8) 4 (1; 0.3) - 20 (8; 2.3) 6 - 20 (9; 2.6) 5 - 20 (4;1.2) 6 - 20 (11; 3.2) 4 (1; 0.3) - 20 (63; 18.2)
Domain VI	5 - 20 (1; 1.4)	4 (5; 1.4) - 20 (8; 2.3)

Note: possible scores range 4 to 20 for both domains and facets

The kurtosis and skewness for the total group of respondents, also shown in Table 8, indicate

that the distribution of respondents across the scores in general is good. The skewness is within its boundary (-1.0 - +1.0) for all facets and domains. The kurtosis appears to be a problem with respect to only one facet: Health and Social Care: Availability and Quality (1.11; see Table 8).

Construct validity

From the global data analyses, it appeared that the WHOQOL-100 discriminated between the healthy and the ill respondents. To establish whether this is also true when only looking at the Dutch data, a discriminant analysis (using prior probability and the direct method) was done in which all WHOQOL-100 facets and domains were entered as independent variables.

It appeared that only five facets, Sleep and Rest, Negative Feelings, Working Capacity, Sexual Activity, and Transport, failed to pass the tolerance test. Using the domains and the remaining facets, it emerged that, in general, more than 80 percent of the cases (85.68%) was classified correctly in either the ill or the healthy group. When looking at the percentage of cases that classified correctly in their own group, it appeared that the WHOQOL-100 better classified the respondents of the ill group (94.4% correct) than the healthy individuals (53.7% correct; see Table 10).

Table 10. Classification results of the discriminant analysis

Actual Group	No. of Cases	Predicted Group Membership	
		0	1
Group 0 healthy group	67	31 53.7%	36 46.3%
Group 1 ill group	303	17 5.6%	286 94.4%
Percent of "grouped" cases correctly classified: 85.68%			

So, it can be concluded that the WHOQOL-100 was reasonably able to discriminate between well and ill persons.

Importance questions

Concerning the 32 importance questions, it appeared that the means across all respondents ranged from 3.07 for Sexual Activity to 4.22 for Activities of Daily Living. With respect to five importance questions every respondent labeled the facets that these questions referred to as being at least "a little important". These importance questions covered the following aspects of QoL: Positive

Feelings, Thinking, Learning, Memory, and Concentration, Home Environment, Health Care and Social Care: Accessibility and Quality, and Physical Environment.

In the case of the other 27 questions, a number of respondents indicated that the facets that these questions referred to were *not important* to them. However, the number of respondents answering Not important to an importance question was low; at the most 30 (7.2%) for the question asking "How important to you is your sexual life?". The number of persons indicating that an aspect was extremely important to them ranged from 21 (5%) for "How important to you is the image of your own body and your appearance?" to 144 (34.5%) for "How important to you is being able to take care of your daily living activities (e.g., washing, dressing, eating)?". There were little missing data for the importance questions (maximum 3.8%) (see Table 11).

Table 11. Number of respondents not responding to the importance questions or judging the various facets as 'not important', or 'extremely important'

	Not important frequency (%)	Extremely important frequency (%)	Missing data
Overall QoL	2 (0.5)	70 (16.8)	4 (1.0)
Health	3 (0.7)	107 (25.7)	4 (1.0)
Free from any pain	15 (3.6)	71 (17.0)	4 (1.0)
Energy	1 (0.2)	116 (27.8)	5 (1.2)
Sexual life	30 (7.2)	19 (4.6)	15 (3.6)
Restful sleep	1 (0.2)	85 (20.4)	4 (1.0)
Feel happy and enjoy life	-	128 (30.7)	3 (0.7)
Feel content	1 (0.2)	95 (22.8)	3 (0.7)
Feel hopeful	2 (0.5)	76 (18.2)	3 (0.7)
Be able to learn and remember important information	1 (0.2)	66 (15.8)	7 (1.7)
Think through everyday problems and taking decisions	-	71 (17.0)	5 (1.2)
Being able to concentrate	1 (0.2)	74 (17.7)	5 (1.2)
Feel positive about oneself	1 (0.2)	46 (11.0)	3 (0.7)
Body image and appearance	8 (1.9)	21 (5.0)	5 (1.2)
Free of negative feelings	12 (2.9)	61 (14.6)	4 (1.0)
Able to move around	5 (1.2)	49 (11.8)	2 (0.5)
Be able to take care of daily living activities	1 (0.2)	144 (34.5)	4 (1.0)
Free of dependence on medication or treatment	14 (3.4)	108 (25.9)	4 (1.0)
Be able to work	5 (1.2)	62 (14.9)	6 (1.4)
Relations with other people	1 (0.2)	67 (16.1)	3 (0.7)
Support from others	1 (0.2)	31 (7.4)	3 (0.7)
Feel physically safe and secure	3 (0.7)	45 (10.8)	3 (0.7)
Home environment	-	53 (12.7)	3 (0.7)
Financial resources	3 (0.7)	37 (8.9)	4 (1.0)
Be able to get adequate health care	-	100 (24.0)	5 (1.2)
Be able to get adequate social help	20 (4.8)	45 (10.8)	16 (3.8)
Chances for getting new information or knowledge	1 (0.2)	35 (8.4)	4 (1.0)
Chances to learn new skills	15 (3.6)	26 (6.2)	5 (1.2)
Relaxation or leisure	2 (0.5)	59 (14.1)	2 (0.5)
Environment (e.g., pollution, climate, ...)	-	48 (11.5)	2 (0.5)
Adequate transport in everyday life	2 (0.5)	70 (16.8)	2 (0.5)
Personal beliefs	11 (2.6)	65 (15.6)	4 (1.0)

Norms

In order to get an idea about the scores that the respondents received on the WHOQOL-100 domains and facets, the mean scores are presented in Table 12. Because the WHOQOL-100 could discriminate fairly good between healthy and ill persons, the scores are presented separately for these two groups of respondents.

Table 12. Average scores and standard deviations of the respondents

WHOQOL-100	Healthy group		Ill group	
	Mean score	SD	Mean	SD
Overall Quality of Life and General Health	14.7	3.3	12.8	3.4
Physical Health	14.9	2.9	12.4	3.0
Pain and Discomfort	9.5	2.7	11.6	3.0
Energy and Fatigue	14.2	3.9	10.9	4.1
Sleep and Rest	15.8	4.0	13.8	3.9
Psychological Health	14.5	1.9	13.8	2.3
Positive Feelings	13.9	2.0	13.2	2.6
Thinking, Learning, Memory, & Concentration	14.4	2.3	13.1	3.1
Self-esteem	13.8	2.3	13.4	2.8
Body Image and Appearance	16.0	2.9	15.5	3.3
Negative Feelings	9.6	3.0	10.2	3.3
Level of Independence	16.1	2.9	12.6	3.3
Mobility	16.6	3.5	13.8	4.2
Activities of Daily Living	16.2	3.2	13.1	4.1
Dependence on Medication or Treatments	7.5	3.7	12.3	4.2
Working Capacity	15.1	3.6	11.9	4.3
Social Relationships	14.3	2.6	13.8	2.7
Personal Relationships	15.1	2.6	14.6	3.0
Social Support	14.1	3.3	13.8	3.4
Sexual Activity	13.6	3.8	13.0	3.6
Environment	15.2	1.5	14.8	2.1
Physical Safety and Security	15.1	2.2	14.9	2.6
Home Environment	15.4	2.6	15.5	3.0
Financial Resources	15.6	3.0	15.3	3.8
Health and Social Care: Availability and Quality	14.3	2.2	13.8	2.8
Opportunities for Acquiring New Information and Skills	15.0	2.3	14.4	2.9
Participation in and Opportunities for Recreation/Leisure	14.9	3.0	14.0	3.2
Physical Environment (pollution/noise/traffic/climate)	14.2	2.3	14.3	2.7
Transport	17.0	3.0	16.0	3.4
Spirituality/Religion/Personal Beliefs	12.7	3.0	12.6	3.6

In the next chapter six studies will be discussed that were done with the WHOQOL-100 in order to further investigate the questionnaire's reliability and validity.

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CHAPTER 6 Reliability and validity of the WHOQOL-100

In this chapter, the data concerning six studies are presented in which the reliability and validity of the Field Trial Version of the WHOQOL, the WHOQOL-100, was investigated. In Study 1, the reliability (internal consistency) and content and construct validity of the instrument was established using a range of questionnaires such as the Sickness Impact Profile (SIP; Bergner, Bobbit, Carter, & Gilson, 1981; Dutch version by Luttik, Jacobs, & De Witte, 1985), the Self-esteem Scale (SES; Rosenberg, 1965; Dutch version by De Vries & Op den Buijs, 1994), and the Profile of Mood States (POMS; McNair, Lorr, & Droppelman, 1981; Dutch version by Wald & Mellenbergh, 1990) among a group of Chronic Fatigue Syndrome (CFS) patients and a healthy group. In Study 2, among a random sample of the general population, the test-retest reliability of the WHOQOL-100 was assessed as well as the construct validity using the General Health Questionnaire-30 (GHQ-30; Goldberg, 1972; Dutch version by Koeter & Ormel, 1991), the Life Satisfaction Index A (LSIA; Neugarten, Havighurst, & Tobin, 1961; Dutch version by De Vries & Van Heck, 1995a) and the Psychological General Well-Being Index (PGWB; Dupuy, 1984; Dutch version by De Vries & Van Heck, 1995b). Study 3 was aimed at assessing the validity of the WHOQOL-100 in elderly persons, especially with respect to the environmental domain. The questionnaires that were used encompassed a Loneliness Scale (LS; De Jong-Gierveld & Kamphuis, 1985) and three scales that were used and constellated by Schwirian and Schwirian (1993) measuring psychological well-being, neighboring, and residential satisfaction. In Study 4, a group of lung disease patients received the WHOQOL-100 as well as the SIP, the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), the Medical Psychological Questionnaire for CARA patients (MPVC; Erdman, Cox, & Duivenvoorden, 1992), and the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). Study 5, an investigation with psoriasis patients, was used to further assess the construct validity, this time using the Psoriasis Disability Index (Finlay & Coles, 1995), and the Ben-Tovim Attitude Questionnaire (BAQ; Ben-Tovim & Walker, 1991, 1992), and to look at the sensitivity of the WHOQOL-100. Finally, in Study 6, persons suffering from rheumatoid arthritis (RA) completed the WHOQOL-100 as well as the RAND-36 (Ware, 1993; Dutch version by Van der Zee & Sanderman, 1993), the POMS, the Pain Cognition List (PCL; Vlaeyen *et al.*, 1989), and some questions concerning pain and activities, to further scrutinize the construct validity.

The groups of respondents in the six studies were selected for a number of different reasons. First, the groups of CFS and RA patients were studied because the author is interested in those

diseases. Second, the group of elderly individuals was selected because two students wanted to replicate a study with elderly persons by Schwirian and Schwirian (1993). They added the WHOQOL-100 to their testbooklets. Concerning the psoriasis and sarcoidosis patients, these groups were included because persons from other institutions wanted to study QoL in these patient populations. Finally, a random sample was tested because other field centres also collected data from a random sample. Persons suffering from a major disease like especially cancer were not studied because it was decided that these patients would be studied simultaneously in several field centres in a later stage.

Concerning the psoriasis, sarcoidosis, and elderly study, the instruments that were used in addition to the WHOQOL-100 were to a large extent selected by the persons conducting these studies.

6.1 Study 1: The chronic fatigue syndrome study

In this first validation study, a wide range of existing measures were used to assess the reliability and validity of the WHOQOL. The respondents were a group of persons suffering from Chronic Fatigue Syndrome (CFS) and a group of healthy individuals. CFS "is a complex disorder whose key symptom is persistent or intermittent fatigue or fatiguability which is disproportionate to exertion and disabling in its effects" (Ray, Weir, Phillips, & Cullen, 1992). It is characterized by the sudden onset of profound, debilitating fatigue and other symptoms that persist for at least 6 months and severely reduce the patient's level of activities of daily living (Scheffers, Johnson, Grafman, Dale, & Straus, 1992).

6.1.1 Method

Subjects

The respondents in this study were recruited in the following way. Potential CFS patients, that is, persons who consider themselves to suffer from CFS, were recruited through the Dutch ME Foundation¹. In addition to their own participation in the study, these patients each had to recruit one control person who did not suffer from CFS. This person had to be of approximately the same age, gender, and educational level as the patient himself/herself. Two hundred and eighteen patients and their control persons received a test-booklet which was completed and returned by 378 persons (194 potential CFS patients and 184 non-CFS persons). This was a response rate of

¹ The author likes to thank the Dutch ME Foundation for their cooperation. ME stands for Myalgic Encephalomyelitis. This term is often used synonymously to CFS

90.7 percent for the group of patients and 86 percent for the other group.

The ME Foundation members had to answer a set of questions concerning their illness which incorporated the Centers for Disease Control-criteria for CFS, the present golden standard for diagnosing CFS (De Bruijn, 1994; Holmes *et al.*, 1988). When the CFS 'diagnosis' was checked using these criteria, it appeared that only 73 of the initial pool of CFS respondents (38%) could be diagnosed as 'real' CFS patients. From these 73 persons, one was removed from the data set because this person had more than 20 percent missing data on the WHOQOL-100. The remaining group of 72 CFS patients as well as the persons from the control group who had indicated not to suffer from *any* disease ($N=143$) were used in this validation study.

Table 1. Demographic characteristics of the respondents

Demographic information	CFS group ($N=72$)	Healthy group ($N=143$)
Sex:		
Female	63 (87.5) ¹	126 (88.1) ¹
Male	9 (12.5)	17 (11.9)
Age:		
Range	21-62	21-74
Mean	39.2	39.4
Standard Deviation	9.5	11.1
Marital Status:		
Married/Living with a partner	45 (62.5)	113 (79.0)
Unmarried/Living alone	27 (37.5)	29 (20.3)
Missing		2 (0.7)
Education level:		
Low	13 (18.1)	39 (27.3)
Middle	39 (54.2)	49 (34.3)
High	20 (27.8)	53 (37.1)
Missing		2 (1.4)
Paid Work:		
Yes	17 (23.6)	102 (71.3)
No	55 (76.4)	41 (28.7)

¹ Percentages are presented parenthetically

In the healthy group as well as the CFS group more than 85 percent of the respondents were female. The age ranges for both groups were fairly similar. The ages ranged from 21 to 62 ($M=39.2$; $SD=9.5$) in the CFS group and 21 to 74 ($M=39.4$; $SD=11.1$) for the healthy group. Whereas 79 percent of the healthy respondents were living with a partner, this was only true for 62.5 percent of the CFS group. Another difference between the two groups was that only 23.6 percent of the ill respondents indicated to do paid work, which, on average, amounted to working five hours a week. In contrast, more than 70 percent of the healthy individuals did paid work.

With respect to the respondents' educational level, only one-fifth of the CFS group was in the lowest category (only 18.1%), while this was true for 27.3 percent of the healthy persons (see Table 1).

Measures

Eight questionnaires were employed. These were the WHOQOL-100, the Profile of Moods States (POMS; McNair *et al.*, 1981; Dutch short version by Wald & Mellenbergh, 1990), the Fatigue Impact Scale (FIS; Fisk *et al.*, 1994a, 1994b), the Social Support Questionnaire (SSQ; Sarason, Levine, Basham, & Sarason, 1983; Dutch translation by Van Heck & Rompa, 1994), and the Sickness Impact Profile (SIP; Bergner *et al.*, 1981; Dutch version by Luttik *et al.*, 1985). In addition, some questions concerning types of social support (De Bruijn, 1994) were asked. Finally, a number of questionnaires that tap into personality characteristics were used: the Self-esteem Scale (SES; Rosenberg, 1965), the Self-oriented Perfectionism and the Socially-oriented Perfectionism scale of the Multiple Perfectionism Scale (MPS; Hewitt & Flett, 1988), the Life Orientation Test (LOT; Scheier & Carver, 1985), the COPE (Carver, Scheier, & Weintraub, 1989; Fontaine, Manstead, & Wagner, 1993), and the Standard Bipolar Big-Five Factor Markers (SBBFFM; Goldberg, 1992; Dutch translation by Van Heck, 1993).

A measure used to validate the WHOQOL-100 questionnaire as a whole was the SIP. The SIP is a widely used health status measure. It consists of 136 items belonging to 12 categories: Ambulation, Mobility, Body Care and Movement (i.e., the physical dimension), Social Interaction, Alertness Behavior, Emotional Behavior, Communication (i.e., the psychosocial dimension), Sleep and Rest, Eating, Work, Home Management, and Recreation and Pastimes. Scores on this instrument are transformed into percentages that indicate the impact of the disease on a person's life. The higher one scores on a scale, the higher the disease impact. The validity and reliability of this measure appear to be good (e.g., Bergner, Bobbit, Carter, & Gilson, 1981; Bowling, 1995; König-Zahn, Furer, & Tax, 1993). In the present study, three SIP scales were left out. The scale Work was not used because most patients (see Table 1) no longer had a job due to their illness. The scales Walking and Eating were left out because the WHOQOL does not have similar facets to match these scales. Thus, the SIP used in this study consisted of 106 items for the remaining nine scales. Since the SIP measures *the impact of illness* on daily life, this measure was only used in the case of the CFS group.

The POMS was used because it measures five different mood states: Depression (8 items), Neuroticism (6 items), Irritation (7 items), Fatigue (6 items), and Vigor (5 items). The first three scales were used to validate the facet Negative Feelings of the WHOQOL, whereas the latter two

were used to validate the facet Energy and Fatigue. The reliability of the five scales ranges from 0.78 for Depression (the item 'Blue' was left out because it decreased the internal consistency considerably) to 0.96 for Fatigue.

Another questionnaire used to validate the facet Energy and Fatigue from the WHOQOL-100 was the FIS. This new 40-item instrument measures three dimensions of fatigue: social, cognitive, and physical fatigue. It was validated on a population of CFS and MS patients (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994a; Fisk *et al.*, 1994b). The FIS distinguishes between groups of patients for which fatigue is a major complaint. In the present study, the internal consistency coefficients of the three dimensions were 0.91 for the cognitive dimension, 0.89 for the social dimension, and 0.79 for the physical one.

The SSQ consists of 27 items. For each item the respondent has to identify the number of people that one "can count on" for a particular type of support. In addition, for each supportive behavior one has to provide, a global rating of satisfaction concerning the availability of the social network. Thus, the SSQ yields two scores: the average number of available support providers, and the average level of satisfaction with the amount of available support (e.g., Dunkel-Schetter & Bennett, 1990; Sarason *et al.*, 1983). Especially the level of satisfaction is very suitable for comparison with the WHOQOL-100 facet Social Support.

The SES contains ten items and is scored using a 4-point response format. Scores can range from 10 to 40, with higher scores indicating higher self-esteem. It is a unidimensional scale with a good reliability and validity (Blascovitch & Tomaka, 1991). In the present study, the internal consistency (Cronbach's alpha) was 0.87. Because of these qualities and the fact that the SES is often used to validate new self-esteem measures, it was used here to validate the WHOQOL-100 facet Self-Esteem.

A Big Five questionnaire, the SBBFFM, was also employed to investigate possible relationships between each personality dimension and WHOQOL-100 scores. Based on the work by Costa and McCrae (1980, 1984) and a study by Headey and Wearing (1989), from which it appeared that Neuroticism, Extraversion, and Openness to Experience predisposed persons to experience moderately stable level of subjective well-being, it might be expected that the WHOQOL-100 is correlated with these three personality dimensions. The SBBFFM was used because it does not take much time to respond, and appears to be reliable and valid (Van Heck, Perugini, Caprara, & Fröger, 1994). It consists of 60 bipolar adjectives, 12 for each of the five dimensions of the Five-Factor Model of personality (Extraversion, Agreeableness, Conscientiousness, Emotional Stability, and Openness to Experience). For each pair of adjectives the respondent has to choose between the two poles and then has to indicate the magnitude to which it applies to him/her. In this study, the internal consistency ranged from 0.76 for Conscientiousness to 0.88 for Extraversion.

Scheier and Carver (1985) developed the Life Orientation Test (LOT), a test which measures dispositional optimism and pessimism. Originally, the LOT was assumed to assess the extent of optimism on a uni-dimensional scale. However, in the present study, an Optimism scale as well as a Pessimism scale was used. Each scale consists of four items, masked by four so-called filler items. The two scales were used separately because the Optimism and Pessimism subscales did not correlate extremely high with one another ($r=-0.35$) and therefore were used separately. In the present study, the internal consistency appeared to be good for both scales, 0.74 and 0.80, respectively, for Optimism and Pessimism.

Finally, several questions were asked which were specifically developed for a study with chronic patients (De Witte *et al.*, 1989). These questions refer to three different kinds of social support: practical support, emotional support, and understanding. In addition, questions regarding each type of support were asked in relation to a whole range of possible support providers such as one's partner, children, and neighbors. The reliability of the three support scales was 0.47 for Understanding, 0.53 for Emotional Support, and 0.61 for Practical Support. For the items, see Appendix XII.

6.1.2 Results

Reliability

The Cronbach's alpha internal consistency of the WHOQOL-100 was calculated for the total group of respondents ($N=215$). It appeared (see Table 2) that the reliability of the facets ranged from 0.43 for Physical Environment to 0.96 for Activities of Daily Living. For the domains, the reliability score ranged from 0.71 for Social Relationships (Domain IV) to 0.93 for Domain III (Level of Independence). Thus, the reliability of the WHOQOL-100 facets and domains is reasonable to very good.

Construct validity

The construct validity was assessed separately for the CFS group and the healthy control group in order to see whether the WHOQOL-100 is a good measure for ill respondents as well as healthy respondents.

The correlation between Facet 6 (Self-Esteem) of the WHOQOL-100 and the SES was highly significant for both the CFS group ($r=0.77$; $p<0.01$) and the healthy group ($r=0.73$; $p<0.01$). Concerning Facet 4 (Positive Feelings) the correlation with LOT-Optimism was about the same for the healthy group and the CFS group, namely 0.51 ($p<0.01$) and 0.43 ($p<0.01$), respec-

tively.

Table 2. Internal consistency of the WHOQOL-100 for the total group

WHOQOL scales	Cronbach's alpha
Facet 0: Overall Quality of Life and General Health	0.91
Domain I: Physical Health	0.80
Facet 1: Pain and Discomfort	0.81
Facet 2: Energy and Fatigue	0.95
Facet 3: Sleep and Rest	0.92
Domain II: Psychological Health	0.82
Facet 4: Positive Feelings	0.85
Facet 5: Thinking, Learning, Memory, and Concentration	0.86
Facet 6: Self-Esteem	0.80
Facet 7: Body Image and Appearance	0.88
Facet 8: Negative Feelings	0.88
Domain III: Level of Independence	0.93
Facet 9: Mobility	0.94
Facet 10: Activities of Daily Living	0.96
Facet 11: Dependence on Medication or Treatments	0.93
Facet 12: Working Capacity	0.94
Domain IV: Social Relationships	0.71
Facet 13: Personal Relationships	0.49
Facet 14: Social Support	0.84
Facet 15: Sexual Activity	0.59
Domain V: Environment	0.84
Facet 16: Physical Safety and Security	0.65
Facet 17: Home Environment	0.77
Facet 18: Financial Resources	0.89
Facet 19: Health and Social Care: Availability and Quality	0.53
Facet 20: Opportunities for Acquiring New Information and Skills	0.78
Facet 21: Participation in and Opportunities for Recreation/Leisure	0.58
Facet 22: Physical Environment (pollution/noise/traffic/climate)	0.43
Facet 23: Transport	0.91
Domain VI: Spirituality/Religion/Personal Beliefs	0.86

For the healthy subjects the correlation between Facet 14 (Social Support) and SSQ-Satisfaction with Social Support was 0.39 ($p < 0.01$). WHOQOL-100-Social Relationships (Domain IV) and WHOQOL-100-Personal Relationships (Facet 13) were also significantly associated with SSQ-Satisfaction with Social Support ($r = 0.50$; $p < 0.001$, and $r = 0.37$; $p < 0.01$, respectively). The correlation between SSQ-Satisfaction with Social Support, on the one hand, and the WHOQOL-100 domain Social Relationships, on the other hand, was also significant ($r = 0.38$; $p < 0.05$) for the CFS group, whereas the correlations with the WHOQOL-100 facets Personal Relationships and Social Support were 0.32 (ns) and 0.22 (ns). Concerning the number of supporters that respondents mentioned in response to the 27 questions of the SSQ, it appeared that for both

groups the correlation with Facet 14 was significant ($r=0.27$; $p<0.01$ for the healthy group, and $r=0.58$; $p<0.001$ for the CFS group). The number of supporters was also significantly correlated with WHOQOL-100-Personal Relationships in the case of the CFS group ($r=0.36$; $p<0.01$). For both groups, the number of supporters was related to WHOQOL-100-Social Relationships ($r=0.25$; $p<0.05$ for the healthy group, and $r=0.47$; $p<0.01$ for the CFS group). Finally, correlations were calculated between Domain IV (Social Relationships) and the social support scales Practical Support, Emotional Support, and Understanding from De Witte *et al.* (1989) for the CFS group only. The results are shown in Table 3.

Practical Support was significantly and positively related to Domain IV at both the domain level (Social Relationships) and the facet level (the facet Social Support). However, at the level of support providers, it appeared that only the practical support that the respondents received from their family and friends were related to the WHOQOL-100 (see Table 3). Practical support from the family was significantly correlated with the entire domain and practical support from friends was significantly related to the Social Relationships domain score and at facet level with Social Support.

Table 3. Correlations between the Social Support scales from De Witte *et al.* (1994) and Domain IV (WHOQOL-100)

	Soc. Rel. ¹	Pers. Rel. ²	Soc. Supp. ³	Sex. Act. ⁴
Practical Support				
Total	0.54*	0.33	0.68**	0.30
Family	0.51***	0.28*	0.57***	0.31*
Children	0.06	0.12	0.22	-0.21
Other patients	0.06	-0.08	0.26	-0.07
Partner	0.12	-0.12	0.17	0.17
Friends	0.33**	0.18	0.46***	0.10
Emotional Support				
Total	0.77***	0.54*	0.84***	0.53*
Family	0.58***	0.32*	0.60***	0.43***
Children	0.16	0.17	0.20	0.02
Other patients	0.09	-0.08	0.18	0.05
Partner	0.26	0.08	0.30*	0.17
Friends	0.52***	0.31*	0.65***	0.19
Understanding				
Total	0.51**	0.37	0.66***	0.23
Family	0.50***	0.30*	0.53***	0.31*
Children	0.06	0.06	0.19	-0.11
Other patients	---	---	---	---
Partner	0.13	-0.00	0.27*	-0.00
Friends	0.44***	0.27*	0.61***	0.09

Note: *** $p<0.001$; ** $p<0.01$; * $p<0.05$; ¹ WHOQOL-Social Relationships (Domain IV); ² WHOQOL-Facet 13, Personal Relationships; ³ WHOQOL-Facet 14, Social Support; ⁴ WHOQOL-Facet 15, Sexual Activity

Emotional Support was strongly related to Domain IV at the domain level as well as with all its facets. Looking at the support providers level, it emerged that emotional support from one's family was significantly correlated with the entire domain IV. Furthermore, emotional support from the partner was related to WHOQOL-100-Social Support ($r=0.30$; $p<0.05$). Moreover, emotional support from friends was related to WHOQOL-100-Social Relationships (i.e., at the domain level), WHOQOL-100-Personal Relationships and WHOQOL-100-Social Support (see Table 3).

Table 4. Correlations between the WHOQOL-facets and the SIP-scales for the CFS group¹

WHOQOL-100	SIP-scales								
	AB	Comm.	EB	HM	BCM	Mob.	RP	SR	SI
Facet 0	-0.18	-0.22	-0.31*	-0.21	-0.14	-0.18	-0.24*	-0.18	-0.31**
Facet 1	0.13	0.15	0.46***	0.17	0.21	0.29*	0.14	0.21	0.47***
Facet 2	-0.13	-0.12	-0.22	-0.29*	-0.05	-0.16	-0.28*	-0.37**	-0.13
Facet 3	-0.20	-0.27*	-0.32**	-0.07	-0.21	-0.26*	-0.25*	-0.33**	-0.33**
Facet 4	0.00	0.02	-0.37**	-0.08	-0.08	-0.17	-0.00	-0.12	-0.40***
Facet 5	-0.68***	-0.40**	-0.25*	0.00	-0.11	-0.18	-0.22	-0.21	-0.19
Facet 6	-0.19	-0.26*	-0.42***	-0.25*	-0.04	-0.20	-0.10	-0.05	-0.34**
Facet 7	0.03	-0.11	-0.43***	-0.09	-0.13	-0.11	-0.12	-0.11	-0.27*
Facet 8	0.15	0.31**	0.71***	0.13	0.19	0.18	0.07	0.21	0.47***
Facet 9	-0.19	-0.21	-0.09	-0.42***	-0.28*	-0.30*	-0.32**	-0.08	-0.20
Facet 10	-0.18	-0.17	-0.35**	-0.38**	-0.26*	-0.30*	-0.29*	-0.33**	-0.31**
Facet 11	0.23	0.18	0.21	0.14	0.36**	0.29*	0.01	0.08	0.06
Facet 12	-0.23*	-0.27*	-0.22	-0.53***	-0.20	-0.37**	-0.35**	-0.23*	-0.36**
Facet 13	-0.09	-0.27*	-0.31**	-0.03	-0.03	-0.11	-0.03	0.08	-0.43***
Facet 14	-0.08	-0.27*	-0.35**	-0.05	-0.16	-0.22	-0.00	-0.08	-0.42***
Facet 15	-0.11	-0.08	-0.04	-0.18	0.16	0.03	-0.09	0.06	-0.17
Facet 16	-0.15	-0.22	-0.45***	0.01	-0.14	-0.16	0.06	-0.06	-0.17
Facet 17	-0.03	-0.13	-0.30*	-0.16	-0.14	-0.32**	-0.13	-0.02	-0.26*
Facet 18	-0.28*	-0.24*	-0.42***	-0.14	-0.26*	-0.16	-0.09	-0.09	-0.19
Facet 19	-0.22	-0.33**	-0.25*	-0.04	-0.13	-0.25*	-0.12	-0.09	-0.05
Facet 20	-0.26*	-0.29*	-0.14	-0.15	-0.14	-0.14	-0.26*	-0.16	-0.18
Facet 21	-0.14	-0.11	-0.27*	-0.24*	0.09	-0.32**	-0.21	-0.25*	-0.38**
Facet 22	-0.03	-0.06	-0.26*	-0.06	-0.11	-0.21	-0.12	-0.20	-0.39**
Facet 23	-0.00	-0.12	0.08	-0.26*	-0.14	-0.32**	-0.07	0.07	-0.18

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; Mob.=Mobility; BCM=Body Care and Movement; SI=Social Interaction, AB=Alertness Behavior; EB=Emotional Behavior; Comm.=Communication; SR=Sleep and Rest; HM=Home Management; RP=Recreation and Pastimes.

¹ The higher the scores on the WHOQOL-100, the higher the level of functioning. In contrast, the higher the scores on the SIP, the higher the level of dysfunctioning.

The latter type of support, Understanding the Patient, was significantly related to Domain IV at the level of scores for the total domain and the particular facet Social Support. Again, patient's

family (at both domain level and facet level of Domain IV), partner (Social Support), and friends (the entire Domain IV except Sexual Activity) had significant and positive correlations with the WHOQOL-100 (see Table 3).

Looking at the correlations between the WHOQOL-100 facets and the SIP-scales, it appeared that the scales that should correlate highly with one another because they seem to measure the same aspect, indeed did so. For instance, the SIP-scale Alertness Behavior correlated -0.68 with the WHOQOL-100 facet Thinking, Learning, Memory, and Concentration (Facet 5).

SIP-Communication also correlated highly with WHOQOL-100-Thinking, Learning, Memory, and Concentration ($r=-0.40$). This might be caused by the fact that the Communication scale contains items that refer to being unable to communicate due to physical problems. Furthermore, SIP-Emotional Behavior correlated highly with the WHOQOL-100 facets Negative Feelings (Facet 8) and Pain and Discomfort (Facet 1), with all correlations in the expected direction. That is, SIP-Emotional Behavior correlated positively with WHOQOL-Negative Feelings (the higher the score, the more negative feelings) and positively with the WHOQOL-100 facet Pain and Discomfort (Facet 1), due to the fact that two out of the nine items of SIP-Emotional Behavior were concerned with pain and discomfort. SIP-Home Management had high negative correlations with the WHOQOL-100 facets Mobility (Facet 9), Activities of Daily Living (Facet 10), and Working Capacity (Facet 12). The WHOQOL-100 facets Mobility (Facet 9) and Dependence on Medication or Treatments (Facet 11) were related to SIP-Body Care and Movement, respectively, in a negative and a positive direction (see Table 4).

The two aspects of the questionnaires measuring mobility correlated -0.30 with one another. However, SIP-Mobility correlated equally high or slightly higher with the WHOQOL-100 facets Activities of Daily Living (Facet 10), Working Capacity (Facet 12), Home Environment (Facet 17), Participation in and Opportunities for Recreation/Leisure (Facet 21), and Transport (Facet 23). SIP-Recreation and Pastimes, that inquires into changes in one's spare time activities like spending more time being passive and meeting less persons, correlated -0.21 with the WHOQOL-100 facet Participation in and Opportunities for Recreation/Leisure (Facet 21), which is more focussed on the respondent's satisfaction with leisure activities. In addition, SIP-Recreation and Pastimes correlated significantly with the WHOQOL-100 facets Energy and Fatigue (Facet 2), Sleep and Rest (Facet 3), Mobility (Facet 9), Activities of Daily Living (Facet 10), Working Capacity (Facet 12), and Opportunities for Acquiring New Information and Skills (Facet 20). Both scales measuring sleep and rest were significantly correlated with each other ($r=-0.33$). The SIP scale Sleep and Rest was also highly significantly correlated with the WHOQOL-100 facets Energy and Fatigue (Facet 2) and Activities of Daily Living (Facet 10). Finally, SIP-Social

Interaction was related to the WHOQOL-100 facets Personal Relationships (Facet 13), Social Support (Facet 14), Negative Feelings (Facet 8), Positive Feelings (Facet 4), and Pain and Discomfort (Facet 1; see Table 4).

Subsequently, the SIP-Physical Functioning Domain score and the SIP-Psychosocial Functioning Domain score were calculated. SIP-Physical Domain consisted of the scales Body Care and Movement and Mobility. Psychosocial Functioning was constellated from four scales: Emotional Behavior, Social Interaction, Alertness Behavior, and Communication. Then, the relationship between these domain scores and the six domains of the WHOQOL-100 were calculated. The results are presented in Table 5. It appeared that the Physical Functioning Domain of the SIP was significantly correlated with the domains Physical Health, Level of Independence, and Environment of the WHOQOL-100. Psychosocial Functioning was related to five out of the six WHOQOL-100 domains. The strongest links were found with the WHOQOL-100 domains Physical Health ($r=0.50$), Psychological Health ($r=0.59$), and Environment ($r=0.50$). Spirituality/Religion/Personal Beliefs was not related to the SIP domains (see Table 5).

Table 5. Correlations between the domains of the WHOQOL-100 and the SIP for the CFS group

WHOQOL-100 domains	SIP-Physical dimension	SIP-Psychosocial dimension
Physical Health	-0.31**	-0.50***
Psychological Health	-0.20	-0.59***
Level of Independence	-0.49***	-0.43***
Social Relationships	-0.05	-0.39**
Environment	-0.35**	-0.50***
Spirituality/Religion/Personal Beliefs	0.09	-0.00

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

In order to establish the construct validity of the facet Negative Feelings of the WHOQOL-100, correlations were calculated between that particular facet and the three scales of the POMS that were intended to measure negative emotions - Depression, Irritation, and Neuroticism - and the scale Pessimism of the LOT. Negative Feelings was positively related to all four measures. The correlations ranged from 0.27 to 0.60. In addition, the correlation between the domain score of Psychological Health and Depression of the POMS was calculated. They appeared to be negatively related to one another ($r=-0.58$; $p < 0.001$).

Table 6. Correlations between the SBBFFM and POMS-Neuroticism, on the one hand, and the WHOQOL-100, on the other hand, for the total group ($N=215$)

WHOQOL-100	BIG FIVE					POMS Neurotic.
	Agree	Cons.	Em.St.	Extr.	Op.Ex.	
Overall Quality of Life and General Health	0.23**	0.20**	0.44***	0.48***	0.14*	-0.41***
Physical Health	0.15*	0.12	0.41***	0.41***	0.07	-0.48***
Pain and Discomfort	-0.09	-0.09	-0.38***	-0.35***	-0.02	0.46***
Energy and Fatigue	0.18*	0.12	0.41***	0.45***	0.08	-0.41***
Sleep and Rest	0.12	0.10	0.29***	0.24***	0.08	-0.42***
Psychological Health	0.24**	0.22**	0.53***	0.46***	0.25***	-0.59***
Positive Feelings	0.26***	0.24**	0.43***	0.43***	0.24***	-0.43***
Thinking, Learning, Memory, and Concentration	0.22**	0.21**	0.46***	0.43***	0.20**	-0.46***
Self-esteem	0.26***	0.23**	0.45***	0.38***	0.30***	-0.48***
Body Image and Appearance	0.08	0.08	0.19*	0.16*	0.16*	-0.29***
Negative Feelings	-0.13	-0.12	-0.48***	-0.33***	-0.12	0.60***
Level of Independence	0.13	0.11	0.37***	0.39***	-0.03	-0.44***
Mobility	0.11	0.06	0.29***	0.37***	0.02	-0.39***
Activities of Daily Living	0.15*	0.11	0.38***	0.42***	0.05	-0.43***
Dependence on Medication or Treatments	-0.05	-0.09	-0.33***	-0.25***	0.00	0.43***
Working Capacity	0.15*	0.12	0.38***	0.41***	0.05	-0.41***
Social Relationships	0.26***	0.21**	0.40***	0.40***	0.12	-0.40***
Personal Relationships	0.27***	0.21**	0.46***	0.43***	0.13	-0.47***
Social Support	0.16*	0.12	0.27***	0.29***	0.04	-0.37***
Sexual Activity	0.26***	0.22**	0.30***	0.32***	0.16*	-0.18**
Environment	0.18*	0.11	0.42***	0.39***	0.10	-0.48***
Physical Safety and Security	0.09	0.11	0.30***	0.17*	0.09	-0.38***
Home Environment	0.22**	0.18*	0.36***	0.27***	0.16*	-0.29***
Financial Resources	0.07	0.05	0.28***	0.18*	-0.04	-0.36***
Health and Social Care: Availability and Quality	0.13	0.03	0.26***	0.32***	0.07	-0.36***
Opportunities for Acquiring New Information and Skills	0.20**	0.15*	0.35***	0.37***	0.10	-0.36***
Participation in and Opportunities for Recreation /Leisure	0.13	0.09	0.35***	0.41***	0.15*	-0.38***
Physical Environment (pollution/noise/traffic/climate)	0.15*	0.09	0.36***	0.20**	0.08	-0.34***
Transport	0.07	-0.01	0.20**	0.23**	0.02	-0.29***
Spirituality/Religion/Personal Beliefs	0.30***	0.21**	0.22**	0.22**	0.17*	-0.04

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; Agree=Agreeableness; Cons.=Conscientiousness; Em.St.=Emotional Stability; Extr.=Extraversion; Op.Ex.=Openness to Experience; Neurotic.=Neuroticism

Subsequently, WHOQOL-100-Energy and Fatigue was correlated with the other two scales of the POMS (Fatigue and Vigor), and with the scales of the FIS for the CFS group. Keeping in mind that the higher the score on the facet Energy and Fatigue, the more energy a person has, the relationship between Energy and Fatigue and the two scales of the POMS were in the expected

direction. That is, WHOQOL-Energy and Fatigue correlated -0.88 ($p < 0.001$) with POMS-Fatigue and 0.72 ($p < 0.001$) with POMS-Vigor. It should be kept in mind that when doing a study with only a healthy or ill group, the correlations between the scales will not be as high as in the present study with a combined group. With respect to the FIS, it emerged that there was a significant correlation between WHOQOL-100-Energy and Fatigue and the two FIS scales Social Dimension ($r = -0.37$; $p < 0.01$) and Physical Dimension ($r = -0.32$; $p < 0.01$). The correlation with the total FIS score ($r = -0.32$; $p < 0.01$) was also significant.

To get an idea about the construct validity of the general facet Overall Quality of Life and General Health, it was correlated with the two scales of the LOT: Optimism and Pessimism. The direction of the relationship was in accordance with what one might expect, that is, negative with Pessimism and positive with Optimism. However, the magnitude of the correlations was not very high: 0.25 ($p < 0.001$) with Optimism and -0.15 ($p < 0.05$) with Pessimism. Due to a lack of spread in the answers of the CFS group on Optimism, the correlations for this group were considerably lower than for the Healthy group. While the correlation between Optimism and Overall Quality of Life and General Health was only 0.17 (*ns*) for the CFS group, it was 0.39 ($p < 0.001$) for the healthy group.

Finally, in order to establish the relationship between the WHOQOL-100 and the so-called Big Five personality factors, correlations were calculated between the WHOQOL-100 and the SBBFFM (see Table 6). The correlations for Agreeableness with the WHOQOL-100 ranged from -0.13 for the WHOQOL-100 facet Negative Feelings to 0.30 for the WHOQOL-100 domain Spirituality/Religion/Personal Beliefs. Looking at Conscientiousness, the correlations ranged from -0.12 (Negative Feelings) to 0.24 (for Positive Feelings). Higher correlations were found between the WHOQOL-100 and Emotional Stability. The highest relations were with Domain II (Psychological Health) and Negative Feelings. The correlations ranged from -0.48 for WHOQOL-100-Negative Feelings to 0.54 for WHOQOL-100-Psychological Health. With respect to Extraversion the correlations were also quite high and ranged from -0.35 (Pain and Discomfort) to 0.48 (Overall Quality of Life and General Health). For the fifth personality factor, Openness to Experience, the correlations were in line with those found for Agreeableness and Conscientiousness. The range was -0.12 (Negative Feelings) to 0.30 (Self-Esteem).

The personality factor Emotional Stability was also measured with the Neuroticism scale of the POMS. Correlations between the WHOQOL-100 and this particular POMS scale (see Table 6) showed that the highest negative correlation of the personality aspect was with WHOQOL-100-Psychological Health ($r = -0.59$), while the highest positive correlation was with the WHOQOL-100 facet Negative Feelings ($r = 0.60$).

Discriminating capacity

In order to get an indication about the discriminating capacity of the WHOQOL-100 a discriminant analysis was done using the facet and domain scores of the questionnaire.

As is shown in Table 7, all cases were correctly classified. That is, the healthy group could be distinguished extremely from the CFS group based on their scores on the facets and domains of the WHOQOL-100.

Table 7. Classification results of the discriminant analysis

Actual Group	No. of Cases	Predicted Group Membership	
		0	1
Group 0 healthy group	101	101 100.0%	0 .0%
Group 1 CFS group	46	0 .0%	46 100.0%

Percent of "grouped" cases correctly classified: 100.00%

In the present study it appeared that with the exception of Spirituality/Religion/Personal Beliefs (Domain VI), Body Image and Appearance (Facet 7) and Physical Safety and Security (Facet 16), the means of all domains and facets of the WHOQOL-100 were most different for CFS patients and healthy persons.

Norms

In order to give a first indication of scores that CFS and healthy respondents will receive on the WHOQOL-100 facets and domains, the average scores and standard deviations of the current CFS group and the current Healthy group are presented separately in Table 8.

Further research, aimed at the collection of more data, is necessary for obtaining more robust estimations of norms.

Table 8. Average scores and standard deviations of the CFS and Healthy group separately

WHOQOL-100	CFS group		Healthy group	
	Mean score	SD	Mean score	SD
Overall Quality of Life & General Health	8.6	2.5	17.1	2.0
Physical Health	9.6	2.0	16.7	1.4
Pain and Discomfort	14.4	2.3	8.2	2.3
Energy and Fatigue	6.5	1.8	16.7	1.7
Sleep and Rest	12.6	4.3	17.7	2.3
Psychological Health	12.8	2.0	15.5	1.7
Positive Feelings	12.6	2.3	15.3	2.0
Thinking, Learning, Memory, & Concentration	9.2	2.4	15.2	2.2
Self-esteem	13.0	2.7	14.8	2.1
Body Image and Appearance	16.3	2.9	16.7	2.5
Negative Feelings	11.2	3.2	8.6	2.6
Level of Independence	9.3	1.9	18.7	1.0
Mobility	10.0	2.5	18.8	1.6
Activities of Daily Living	7.7	2.1	18.4	1.5
Dependence on Medication or Treatments	11.3	4.2	4.6	1.1
Working Capacity	6.7	2.2	18.2	1.8
Social Relationships	13.3	2.5	15.9	2.1
Personal Relationships	13.7	2.7	16.7	2.2
Social Support	13.8	3.7	16.3	2.6
Sexual Activity	12.5	3.4	14.8	2.7
Environment	13.4	1.6	16.5	1.5
Physical Safety and Security	15.1	2.3	15.8	1.9
Home Environment	15.3	2.5	16.9	2.4
Financial Resources	13.8	3.8	16.6	2.9
Health & Social Care: Availability & Quality	11.1	2.9	15.1	2.2
Opportunities for Acquiring New Information & Skills	12.1	2.2	16.8	2.2
Participation in & Opportunities for Recreation/Leisure	11.6	3.0	16.8	2.2
Physical Environment (pollution/noise/traffic/climate)	14.4	2.7	15.7	2.2
Transport	13.5	3.6	18.3	2.2
Spirituality/Religion/Personal Beliefs	13.2	3.4	13.6	3.4

6.2 Study 2: The general population study

In this second study, the (test-retest) reliability as well as the content and construct validity were established using a random sample of persons. In addition, indications for norms for scores on the WHOQOL-100 were calculated.

6.2.1 Method

Subjects

Five students were given instructions to call persons at home. Each student had their 'own' house-

number that they were instructed to call. In addition, each of them had an instruction to call the persons living at this particular housenumber in the Xth street in the Yth column of the Zth page of the zipcode book. Five hundred and twenty-eight persons were called and asked whether they would like to participate in a study on QoL. Two hundred and forty (45.5%) were willing to participate. More than 170 respondents of these volunteers ($N=178$; 74.2%) returned their test-booklet of which 142 persons also were prepared to fill out the WHOQOL-100 again after four weeks. Of these 142 individuals, 116 (81.7%) actually returned the test-booklet for the second time.

In the group of persons who returned their test-booklets at Time 1, 59.4 percent were women and more than three-quarter (77.7%) of the respondents were living with a partner. The ages ranged from 18 to 87 years of age ($M=43.48$; $SD=15.1$). In addition, nearly 40 percent (39.4%) had a low level of education, while one-quarter (25.7%) of the individuals had a high education level. Finally, 22.3 percent of the group indicated to suffer from a chronic illness like psoriasis, a respiratory disease, or rheumatoid arthritis. The respondents who also participated the second time did not differ from the entire group at Time 1 with respect to demographic characteristics.

Measures

In the present study, the WHOQOL-100 as well as the Life Satisfaction Index A (LSIA; Neugarten *et al.*, 1961), the General Health Questionnaire-30 (GHQ-30; Goldberg, 1972; Dutch version by Koeter & Ormel, 1991), and the Psychological General Well-Being Index (PGWB; Dupuy, 1984) were employed. These last three measures are all well-being measures and were used in the present study to validate the WHOQOL-100.

The GHQ-30 measures psychological distress. It is one of the versions of the General Health Questionnaire. This particular 30-item version was chosen because it does not take as much time as the original 60-item version, but, on the other hand, is still long enough to guarantee a good reliability (Koeter & Ormel, 1991). Up to now, a considerable number of studies have used this questionnaire. In general, the GHQ-30 appears to have a good reliability and validity. The response scale consists of four answers of which two indicate psychological distress. The scoring format of each question is then transformed into a dichotomous scale; the possible range of scores on the GHQ-30 is 0 - 30. The higher the score, the more a person is psychologically distressed. In the present study the reliability of this scale was 0.93 (Cronbach's alpha).

The LSIA was developed for measuring subjective psychological well-being in the elderly, independently of a person's level of activity or social participation. According to Neugarten and colleagues (1961), the concept *psychological well-being* consists of five components: (i) zest

versus apathy, (ii) resolution and fortitude, (iii) congruence between desired and achieved goals, (iv) positive self-concept, and (v) mood tone. These five components have been labelled *life satisfaction* (Neugarten *et al.*, 1961). However, in several factor analyses these five factors have failed to emerge (e.g., Andrews & Robinson, 1991). For instance, Shmotkin (1991) found three factors, namely Zest, Mood Tone, and Congruence. For the present study, the LSIA was translated into Dutch (De Vries & Van Heck, 1995a). It consists of 20 statements with which one can agree or disagree. If persons are not sure which of the two responses they want to chose, they can answer "?". The respondent gets a score of 1 for each answer that indicates life satisfaction. So, the possible scoring range is 0 - 20, with 20 meaning total satisfaction with life. In the present study, the internal consistency (Cronbach's alpha) of the LSIA was 0.77. The mean score was 12.13 ($SD=3.89$) for the total group and 12.54 ($SD=3.23$) for the respondents over 55 years of age. The respondents who were younger than 55 years of age did not differ from the older respondents ($t=-0.88$; $p=0.38$).

The PGWB, developed by Dupuy in 1984 and translated for the present study by De Vries and Van Heck (1995b), consists of six subscales with each three to five items with a response scale ranging from 0 to 5. The subscales are Anxiety (5 items), Vitality (4 items), Depressed Mood (3 items), Positive Well-being (4 items), Self-control (3 items), and General Health (3 items). In addition, a total PGWB score can be obtained. The reliability and validity of this instrument appears to be good (Bowling, 1995; Dupuy, 1984). In this study, the internal consistency ranged from 0.68 for the subscale Self-control to 0.89 for the subscale Anxiety. For the total PGWB score the reliability was 0.89.

6.2.2 Results

Reliability

First, the internal consistency of the facets and domains of the WHOQOL-100 was calculated (see Table 9). Again the reliability of the WHOQOL-100 was good: Cronbach alpha's ranged from 0.63 for Personal Relationships to 0.93 for Dependence on Medication or Treatments and Working Capacity. With regard to the domains the range of alpha's was 0.65 (Physical Health) to 0.86 (Spirituality/Religion/Personal Beliefs).

Table 9. Internal consistency of the WHOQOL-100

WHOQOL scales	Cronbach's alpha
Facet 0: Overall Quality of Life and General Health	0.79
Domain I: Physical Health	0.65
Facet 1: Pain and Discomfort	0.66
Facet 2: Energy and Fatigue	0.87
Facet 3: Sleep and Rest	0.92
Domain II: Psychological Health	0.77
Facet 4: Positive Feelings	0.80
Facet 5: Thinking, Learning, Memory, and Concentration	0.74
Facet 6: Self-Esteem	0.70
Facet 7: Body Image and Appearance	0.87
Facet 8: Negative Feelings	0.83
Domain III: Level of Independence	0.85
Facet 9: Mobility	0.83
Facet 10: Activities of Daily Living	0.80
Facet 11: Dependence on Medication or Treatments	0.93
Facet 12: Working Capacity	0.93
Domain IV: Social Relationships	0.77
Facet 13: Personal Relationships	0.63
Facet 14: Social Support	0.78
Facet 15: Sexual Activity	0.89
Domain V: Environment	0.80
Facet 16: Physical Safety and Security	0.71
Facet 17: Home Environment	0.75
Facet 18: Financial Resources	0.90
Facet 19: Health and Social Care: Availability and Quality	0.76
Facet 20: Opportunities for Acquiring New Information and Skills	0.71
Facet 21: Participation in and Opportunities for Recreation/Leisure	0.83
Facet 22: Physical Environment (pollution/noise/traffic/climate)	0.67
Facet 23: Transport	0.88
Domain VI: Spirituality/Religion/Personal Beliefs	0.86

Test-retest reliability was measured employing a four-week interval. At the facet level, the test-retest reliability ranged from 0.55 for Working Capacity to 0.87 for Financial Resources. At the domain level, the range was 0.72 (Domain III) to 0.86 (Domain I; see Table 10).

Table 10. Test-retest reliability of the WHOQOL with a four-week interval

Domains and Facets of the WHOQOL-100	Correlation between Times 1 & 2
Overall Quality of Life and General Health	0.81
Domain I: Physical Health	0.86
Pain and Discomfort	0.68
Energy and Fatigue	0.81
Sleep and Rest	0.82
Domain II: Psychological Health	0.83
Positive Feelings	0.77
Thinking, Learning, Memory, and Concentration	0.79
Self-Esteem	0.67
Body Image and Appearance	0.84
Negative Feelings	0.72
Domain III: Level of Independence	0.72
Mobility	0.60
Activities of Daily Living	0.63
Dependence on Medication or Treatments	0.82
Working Capacity	0.55
Domain IV: Social Relationships	0.79
Personal Relationships	0.76
Social Support	0.58
Sexual Activity	0.85
Domain V: Environment	0.83
Physical Safety and Security	0.64
Home Environment	0.79
Financial Resources	0.87
Health and Social Care: Availability and Quality	0.73
Opportunities for Acquiring New Information and Skills	0.58
Participation in and Opportunities for Recreation/Leisure	0.78
Physical Environment (pollution/noise/traffic/climate)	0.63
Transport	0.83
Domain VI: Spirituality/Religion/Personal Beliefs	0.74

Content validity

When the domain scores were correlated with each other, it appeared that Domain VI (Spirituality/Religion/Personal Beliefs) was independent from the other domains (see Table 11). The remaining five domains, were all significantly correlated with one another ($p < 0.01$), with correlations ranging from 0.38 (Level of Independence and Social Relationships) to 0.71 (Physical Health and Level of Independence).

Table 11. Correlations between the WHOQOL domains

	Psychol. Health	Level of Indep.	Social Rel.	Envir.	Spir/Rel/PB
Physical Health	0.63***	0.71***	0.47***	0.41***	0.01
Psychological Health		0.60***	0.55***	0.57***	0.12
Level of Independence			0.38***	0.54***	0.11
Social Relationships				0.53***	0.01
Environment					0.04

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; Psychol. Health = Psychological Health; Level of Indep. = Level of Independence; Social Rel. = Social Relationships; Envir. = Environment; Spir/Rel/PB = Spirituality/Religion/Personal Beliefs.

When the correlations between the facets and domains were calculated, it appeared that all facets correlated highest with the intended domain. In addition, the global facet Overall Quality of Life and General Health correlated between 0.62 (Social Relationships) and 0.71 (Level of Independence) with the domains. An exception was Spirituality/Religion/Personal Beliefs with which it only correlated 0.10 (*ns*).

However, because there was a confounding effect in these correlations between facets and their domains, new domain scores were calculated. The following pattern of correlations between facets and total domain scores, excluding the particular facet, was obtained. For instance, within Domain I three new domain scores were calculated: one without Facet 1, one without Facet 2, and one without Facet 3. These three new scores as well as the other domain scores, in this case Domain II to Domain VI, were correlated with Facet 1, Facet 2, and Facet 3. This procedure was done for all domains except Domain VI, because this domain only contains one facet. The results are presented in Table 12.

Facet 1 (Pain and Discomfort) correlated -0.45 with its own domain. The only domain with which it correlated higher than its own domain, was Level of Independence (Domain III). The facets Energy and Fatigue (Facet 2) and Sleep and Rest (Facet 3) both correlated higher with the domains Psychological Health and Level of Independence than with the corrected Domain I.

Concerning Domain II (Psychological Health), only Facet 4 (Positive Feelings) correlated higher with another domain than its own domain. The other four facets correlated highest with their own domain (see Table 12). With respect to the Domains III (Level of Independence) and IV (Social Relationships), all facets correlated highest with their respective corrected domains.

Table 12. Correlations of the facets of the WHOQOL-100 with the domains corrected for the confounding effects

	Domain I	Domain II	Domain III	Domain IV	Domain V	Domain VI
Facet 1	-0.45	-0.41	-0.55	-0.29	-0.29	-0.00 ^{ns}
Facet 2	0.48	0.58	0.64	0.43	0.34	-0.02 ^{ns}
Facet 3	0.42	0.45	0.43	0.37	0.32	-0.02 ^{ns}
Facet 4	0.46	0.57	0.46	0.61	0.60	0.15 [*]
Facet 5	0.32	0.44	0.42	0.32	0.40	0.12 ^{ns}
Facet 6	0.47	0.71	0.43	0.46	0.41	0.11 ^{ns}
Facet 7	0.41	0.42	0.31	0.24 ^{**}	0.27	-0.00 ^{ns}
Facet 8	-0.62	-0.63	-0.57	-0.42	-0.44	-0.07 ^{ns}
Facet 9	0.48	0.36	0.60	0.26 ^{**}	0.48	0.12 ^{ns}
Facet 10	0.67	0.62	0.76	0.35	0.48	0.07 ^{ns}
Facet 11	-0.57	-0.39	-0.68	-0.20 ^{**}	-0.36	-0.14 ^{ns}
Facet 12	0.62	0.61	0.69	0.44	0.47	0.03 ^{ns}
Facet 13	0.47	0.61	0.43	0.67	0.56	0.07 ^{ns}
Facet 14	0.34	0.41	0.32	0.61	0.45	0.05 ^{ns}
Facet 15	0.39	0.38	0.25 ^{**}	0.55	0.36	-0.07 ^{ns}
Facet 16	0.36	0.36	0.37	0.26	0.35	-0.03 ^{ns}
Facet 17	0.23 ^{**}	0.42	0.35	0.40	0.63	0.00 ^{ns}
Facet 18	0.23 ^{**}	0.35	0.27	0.35	0.54	0.05 ^{ns}
Facet 19	0.34	0.35	0.36	0.43	0.58	0.00 ^{ns}
Facet 20	0.28	0.44	0.48	0.27	0.54	0.13 ^{ns}
Facet 21	0.41	0.53	0.47	0.55	0.64	0.01 ^{ns}
Facet 22	0.11 ^{ns}	0.22 ^{**}	0.21 ^{**}	0.22 ^{**}	0.43	-0.03 ^{ns}
Facet 23	0.23 ^{**}	0.33	0.35	0.25 ^{**}	0.42	0.01 ^{ns}

Note: With exception of the correlations marked with ** ($p < 0.01$) and ^{ns}, the correlations are significant at $p < 0.001$ level

The results with respect to Domain V (Environment) are also presented in Table 12. It appeared that seven of the eight facets showed a higher correlation with their own corrected domain score than with the other domains. Only Facet 16 (Physical Safety and Security) was more related to three other domains, namely Physical Health (Domain I), Psychological Health (Domain II) and Level of Independence (Domain III).

Construct validity

In order to get information about the construct validity of the WHOQOL-100, the scores for facets and domains were correlated with the other three questionnaires, namely the GHQ-30, LSIA, and the PGWB.

As can be seen in Table 13, the only aspects of the WHOQOL-100 with which the GHQ-30 was not significantly correlated were Spirituality/Religion/Personal Beliefs (Domain VI) and Transport

(Facet 23). The lowest significant relation between the WHOQOL-100 and the GHQ-30 was found for Level of Independence at the domain level ($r=-0.41$) and Physical Safety and Security at the facet level ($r=-0.21$). All relationships were in the expected direction, i.e., mostly negative, because the GHQ-30 measures psychological distress whereas the WHOQOL-100 measures QoL. In addition, since the GHQ-30 measures *psychological* distress, it was expected to have the highest correlation with Domain II. Looking at Table 13, it becomes clear that this is exactly what emerged. Psychological Health and GHQ-30 correlated -0.55 with each other. Furthermore, Positive feelings and Negative feelings, both belonging to the domain Psychological Health, were the facets that correlated highest with the GHQ-30 ($r=-0.52$ and $r=0.53$, respectively). Finally, the global facet Overall QoL and General Health, correlated -0.49 with the GHQ-30.

Table 13 also shows the correlations of the WHOQOL-100 with the LSIA. It appeared that, like the GHQ-30, the LSIA was not related to Spirituality/Religion/Personal Beliefs (Domain VI). In addition, the LSIA was not correlated with the facet Physical Environment, but it was related to all other facets of the WHOQOL-100. The lowest significant correlation was found with the domain Social Relationships ($r=0.45$). At the facet level this happened to be with the facet Transport ($r=0.21$). As can be seen, the correlations with all other domains and facets ranged from modest links to very substantial associations. For instance, the LSIA correlated as high as 0.60 with Psychological Health (Domain II). The correlation with Positive Feelings (Facet 4) was of the same magnitude. Based on the components of the LSIA, high correlations were expected with the facets Self-Esteem, Body Image and Appearance, Negative Feelings, Participation in and Opportunities for Recreation/Leisure, and especially the general facet Overall QoL and General Health. With the exception of Body Image and Appearance, which only had a correlation of 0.24 with the LSIA, these correlations were indeed high; ranging from 0.47 for Self-Esteem to 0.65 for Overall QoL and General Health.

Finally, Table 13 shows the correlations between the total PGWB-score and the facets and domains of the WHOQOL-100. The only part of the WHOQOL-100 that the total PGWB-score was not related to, was Domain VI (Spirituality/Religion/Personal Beliefs). The correlations with the other five domains ranged from 0.48 for Level of Independence (Domain III) to 0.74 for Psychological Health (Domain II). Looking at the WHOQOL-100 facets, it appeared that the total PGWB-score correlated highest (-0.71) with WHOQOL-100-Negative Feelings and slightly lower with WHOQOL-100-Overall QoL and General Health (0.69).

Table 13. Correlations between GHQ-30, LSIA, PGWB-Total, and the WHOQOL-100

WHOQOL-100	GHQ-30	LSIA	PGWB-Total
Overall Quality of Life and General Health	-0.49***	0.65***	0.69***
Physical Health	-0.44***	0.47***	0.68***
Pain and Discomfort	0.27***	-0.32***	-0.47***
Energy and Fatigue	-0.43***	0.44***	0.65***
Sleep and Rest	-0.31***	0.31***	0.44***
Psychological Health	-0.55***	0.60***	0.74***
Positive Feelings	-0.52***	0.60***	0.61***
Thinking, Learning, Memory, and Concentration	-0.29**	0.41***	0.36***
Self-esteem	-0.44***	0.47***	0.55***
Body Image and Appearance	-0.26***	0.24**	0.43***
Negative Feelings	0.53***	-0.51***	-0.71***
Level of Independence	-0.41***	0.49***	0.61***
Mobility	-0.23**	0.34***	0.36***
Activities of Daily Living	-0.37***	0.43***	0.63***
Dependence on Medication or Treatments	0.22**	-0.37***	-0.45***
Working Capacity	-0.51***	0.48***	0.59***
Social Relationships	-0.42***	0.45***	0.48***
Personal Relationships	-0.52***	0.52***	0.63***
Social Support	-0.30***	0.35***	0.35***
Sexual Activity	-0.26***	0.27***	0.28***
Environment	-0.43***	0.53***	0.53***
Physical Safety and Security	-0.21**	0.28**	0.39***
Home Environment	-0.28***	0.40***	0.37***
Financial Resources	-0.34***	0.46***	0.37***
Health and Social Care: Availability and Quality	-0.27***	0.33***	0.34***
Opportunities for Acquiring New Information and Skills	-0.31***	0.40***	0.34***
Participation in and Opportunities for Recreation/Leisure	-0.49***	0.57***	0.58***
Physical Environment (pollution/noise/traffic/climate)	-0.22**	0.13	0.22**
Transport	-0.12	0.21**	0.17*
Spirituality/Religion/Personal Beliefs	-0.01	0.11	0.06

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

Subsequently, correlations were calculated between the six PGWB-sub scales and the WHOQOL-100. The results are shown in Table 14. With the exception of Spirituality/Religion/Personal Beliefs, the correlations between the WHOQOL-100 at the domain level and the scales of the PGWB ranged from 0.29 (Social Relationships with General Health) to 0.70 (Psychological Health with PGWB-Positive Well-Being). Psychological Health was the domain that showed the highest correlation with the scales Anxiety, Depressed Mood, Positive Well-being, and Self-control. The PGWB scales General Health and Vitality both correlated highest with domain I, Physical Health: 0.66 and 0.69, respectively.

At the facet level, the correlations ranged from 0.11 (WHOQOL-100-Transport with PGWB-Anxiety) to 0.77 (WHOQOL-100-Energy and fatigue with PGWB-Vitality). Both PGWB-Anxiety and PGWB-Depressed Mood had the highest correlation with WHOQOL-100-Negative feelings: -0.62 and -0.71, respectively. These correlations were negative because a high score on PGWB-

Anxiety and PGWB-Depressed Mood means that the respondent is not anxious or depressed. In contrast, having a high score on WHOQOL-100-Negative Feelings indicates that one has a lot of negative feelings.

Table 14. Correlations between the PGWB-scales and the WHOQOL-100

WHOQOL-100	PGWB-scales					
	Anxiety	Depressed Mood	General Health	Pos. Well-Being	Self-Control	Vitality
Facet 0	0.49***	0.64***	0.52***	0.68***	0.50***	0.58***
Domain I	0.47***	0.50***	0.66***	0.56***	0.49***	0.69***
Facet 1	-0.34***	-0.30***	-0.66***	-0.40***	-0.21**	-0.36***
Facet 2	0.41***	0.51***	0.49***	0.54***	0.46***	0.77***
Facet 3	0.32***	0.31***	0.38***	0.35***	0.41***	0.42***
Domain II	0.55***	0.69***	0.42***	0.70***	0.64***	0.64***
Facet 4	0.45***	0.63***	0.28***	0.67***	0.50***	0.51***
Facet 5	0.24**	0.27***	0.26**	0.35***	0.35***	0.39***
Facet 6	0.35***	0.51***	0.28***	0.55***	0.52***	0.55***
Facet 7	0.31***	0.39***	0.28***	0.41***	0.40***	0.36***
Facet 8	-0.62***	-0.71***	-0.41***	-0.61***	-0.57***	-0.55***
Domain III	0.42***	0.51***	0.63***	0.49***	0.44***	0.57***
Facet 9	0.24**	0.22**	0.57***	0.29**	0.21**	0.31***
Facet 10	0.45***	0.53***	0.50***	0.49***	0.49***	0.56***
Facet 11	-0.32***	-0.38***	-0.59***	-0.31***	-0.31***	-0.41***
Facet 12	0.39***	0.55***	0.42***	0.52***	0.44***	0.59***
Domain IV	0.33***	0.43***	0.29***	0.54***	0.31***	0.45***
Facet 13	0.46***	0.56***	0.34***	0.66***	0.51***	0.55***
Facet 14	0.22**	0.32***	0.26**	0.39***	0.18*	0.39***
Facet 15	0.19*	0.25***	0.17*	0.35***	0.17*	0.25**
Domain V	0.44***	0.52***	0.38***	0.49***	0.41***	0.37***
Facet 16	0.35***	0.32***	0.42***	0.34***	0.26***	0.29***
Facet 17	0.28***	0.43***	0.19*	0.38***	0.31***	0.24**
Facet 18	0.36***	0.40***	0.20**	0.34***	0.31***	0.21**
Facet 19	0.23**	0.28***	0.30***	0.37***	0.17*	0.28***
Facet 20	0.28***	0.31***	0.30***	0.28***	0.33***	0.26**
Facet 21	0.48***	0.57***	0.29***	0.52***	0.47***	0.39***
Facet 22	0.18*	0.18*	0.17*	0.22**	0.14	0.20**
Facet 23	0.11	0.18*	0.14	0.19*	0.14	0.13
Domain VI	0.06	0.01	-0.01	0.10	0.14	0.06

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; Pos.Well-Being=Positive Well-Being

Although PGWB-General Health correlated 0.52 with Overall QoL and General Health of the WHOQOL-100, it had its highest correlation with the WHOQOL-100 facet Pain and Discomfort (-0.66). For PGWB-Positive Well-being, the highest relation was with WHOQOL-100-Overall QoL and General Health (0.68) closely followed by WHOQOL-100-Positive Feelings (0.67). As shown in Table 14, PGWB-Self-control correlated -0.57 with the WHOQOL-100 facet Negative Feelings, 0.52 with the facet Self-Esteem, and 0.50 with the facets Positive Feelings and Overall

QoL and General Health. The last PGWB scale, Vitality, had a correlation of 0.77 with the WHOQOL-100 facet Energy and Fatigue.

Norms

In order to get a first indication of scores that randomly selected persons will receive on the facets and domains of the WHOQOL-100, the average scores and standard deviations of the current respondents were calculated. They are presented in Table 15.

Table 15. Average scores and standard deviations of the respondents in the random sample

WHOQOL-100	Mean score	SD
Overall Quality of Life and General Health	15.9	2.5
Physical Health	15.3	2.3
Pain and Discomfort	9.5	2.7
Energy and Fatigue	14.7	3.1
Sleep and Rest	16.8	3.3
Psychological Health	14.9	1.9
Positive Feelings	14.4	2.1
Thinking, Learning, Memory, & Concentration	14.9	2.6
Self-esteem	14.2	2.2
Body Image and Appearance	16.3	3.1
Negative Feelings	9.5	3.0
Level of Independence	17.2	2.4
Mobility	17.4	2.9
Activities of Daily Living	16.6	2.7
Dependence on Medication or Treatments	6.1	3.0
Working Capacity	16.7	3.2
Social Relationships	15.4	2.5
Personal Relationships	16.0	2.5
Social Support	15.5	3.0
Sexual Activity	14.8	3.6
Environment	15.7	1.8
Physical Safety and Security	15.8	2.2
Home Environment	15.7	2.5
Financial Resources	16.0	3.4
Health and Social Care: Availability and Quality	14.9	2.6
Opportunities for Acquiring New Information and Skills	15.5	2.5
Participation in and Opportunities for Recreation/Leisure	15.7	3.0
Physical Environment (pollution/noise/traffic/climate)	14.8	2.4
Transport	17.3	3.0
Spirituality/Religion/Personal Beliefs	12.7	3.5

6.3 Study 3: The elderly persons study²

In a third validation study with the WHOQOL-100, again construct validity was investigated. Here measures were used to validate especially the domains Psychological Health (Domain II) and Environment (Domain V).

6.3.1 Method

Subjects

Persons were randomly selected using a telephone book. The respondents had to be 55 years or older. They all lived in the southern part of The Netherlands. Three hundred test-booklets were sent to persons who had agreed to participate in this study. One-hundred and seventy-eight (59.3%) actually completed and returned their test-booklet.

The majority of the respondents lived together with a partner (70.8%). In addition, 60.1 percent was female and ages ranged from 60 to 91 years (\underline{M} =69.69; \underline{SD} =6.3). Only nine persons (5.1%) had a high level of education; most had only a low education (68.9%).

Measures

Besides the WHOQOL-100, a Loneliness Scale (LS; De Jong-Gierveld & Kamphuis, 1985) was administered together with three scales that were used by Schwirian and Schwirian (1993) in their study with elderly persons: a 14-item Emotional Well-Being scale derived from various questionnaires (Bradburn, 1969; Hathaway & McKinley, 1943; Lawton, Kleban, & diCarlo, 1984; Neugarten *et al.*, 1961; Rosenberg, 1965), a 6-item Neighboring scale (Ahlbrandt, 1984), and a Residential Satisfaction scale containing items from Ahlbrandt (1984) and Bohland and Herbert (1983).

The LS consists of 11 items with a 5-point response scale ranging from *yes!* to *no!*. In the present study, the internal consistency was 0.89 (Cronbach's alpha).

The Emotional Well-Being scale used by Schwirian and Schwirian (1993) contained two items from the Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI; Lawton *et al.*, 1984). Furthermore, four items were derived from the LSIA and two from the SES. Both instruments were already discussed in paragraph 6.2.1. In addition, two statements came from the Minnesota Multiphasic Personality Inventory (MMPI; Hathaway & McKinley, 1943). Finally, two items were derived from the Affect Balance Scale (ABS; Bradburn, 1969). The reliability of this

² I would like to thank Anneke de Jong and Anne-marieke Jeuken for collecting the data

newly composed Emotional Well-Being scale was 0.74 (internal consistency). Based on factor analysis, Schwirian and Schwirian (1993) stated that this Emotional Well-being consisted of two subscales: Satisfaction and Activity. In the present study, the internal consistency of these subscales were 0.75 and 0.43, respectively. The scales are presented in Appendix XIII.

From the six items of the Neighboring scale five were taken from Ahlbrandt's Neighboring Support Study (1984) and one was added by Schwirian and Schwirian (1993). The internal consistency of this Neighboring scale was 0.57 (see Appendix XIII).

Residential Satisfaction was assessed by items from Ahlbrandt (1984) and Bohland and Herbert (1983) that measured four different aspects: Safety (3 items), Physical Condition (5 items), Proximity (6 items), and General Rating of Home Environment and Satisfaction with the House (2 items). In the present study, the internal consistency of these four subscales were: 0.30, 0.45, 0.66, and 0.66, respectively. In the original study by Schwirian and Schwirian (1993), the reliability of the Residential Satisfaction scales was better. For the present study this means that the results concerning the scales Safety and Physical Condition will have to be interpreted with caution. The scales are presented in Appendix XIII.

6.3.2 Results

Reliability

As in the two validation studies reported earlier, the internal consistency of the facets and domains of the WHOQOL-100 were calculated. The reliability of the WHOQOL-100 was good. At the facet level the internal consistency ranged from 0.54 for Personal Relationships to 0.91 for Sleep and Rest and Working Capacity. With regard to the domains the alpha's ranged from 0.53 (Social Relationships) to 0.91 (Spirituality/Religion/Personal Beliefs; see Table 16).

Construct validity

In this study, construct validity of the WHOQOL-100 was investigated in the following way. The LS, the Emotional Well-Being scale, the four Residential Satisfaction scales, and the Neighboring scale were all correlated with the global QoL facet. In addition, the LS was correlated with the two domains Psychological Health and Social Relationships at the facet as well as the domain level. The Emotional Well-Being scale was also used to validate the domain Psychological Health at both the facet and the domain level. Furthermore, Domain V (Environment) was validated by means of the scales for Residential Satisfaction and Neighboring. The results are presented in the Tables 17 to 20.

Table 16. Internal consistency of the WHOQOL-100

WHOQOL scales	Cronbach's alpha
Facet 0: Overall Quality of Life and General Health	0.83
Domain I: Physical Health	0.61
Facet 1: Pain and Discomfort	0.78
Facet 2: Energy and Fatigue	0.84
Facet 3: Sleep and Rest	0.91
Domain II: Psychological Health	0.78
Facet 4: Positive Feelings	0.71
Facet 5: Thinking, Learning, Memory, and Concentration	0.75
Facet 6: Self-Esteem	0.72
Facet 7: Body Image and Appearance	0.84
Facet 8: Negative Feelings	0.79
Domain III: Level of Independence	0.87
Facet 9: Mobility	0.83
Facet 10: Activities of Daily Living	0.86
Facet 11: Dependence on Medication or Treatments	0.79
Facet 12: Working Capacity	0.91
Domain IV: Social Relationships	0.53
Facet 13: Personal Relationships	0.54
Facet 14: Social Support	0.77
Facet 15: Sexual Activity	0.78
Domain V: Environment	0.79
Facet 16: Physical Safety and Security	0.70
Facet 17: Home Environment	0.69
Facet 18: Financial Resources	0.85
Facet 19: Health and Social Care: Availability and Quality	0.68
Facet 20: Opportunities for Acquiring New Information and Skills	0.74
Facet 21: Participation in and Opportunities for Recreation/Leisure	0.72
Facet 22: Physical Environment (pollution/noise/traffic/climate)	0.66
Facet 23: Transport	0.88
Domain VI: Spirituality/Religion/Personal Beliefs	0.91

As can be seen in Table 17, LS was indeed related to the WHOQOL-100 global facet. In addition, LS was significantly correlated with WHOQOL-100 Domain II (Psychological Health) at the domain as well as the facet level. With respect to the WHOQOL-100 Domain IV (Social Relationships), there was only one facet with which LS was not related, namely the facet Sexual Activity. When the correlations between LS and the other WHOQOL-100 facets and domains were calculated, it appeared that, in general, only the relationship with the domain score Environment ($r=-0.47$; $p<0.001$) and its facet Participation in and Opportunities for Recreation/Leisure ($r=-0.49$; $p<0.001$) were higher.

Table 17. Correlations between the LS and the global facet and two domains of the WHOQOL-100

WHOQOL-100	Loneliness scale ¹
Overall Quality of Life and General Health	-0.43***
Psychological Health	-0.52***
Positive Feelings	-0.49***
Thinking, Learning, Memory, & Concentration	-0.24**
Self-esteem	-0.40***
Body Image and Appearance	-0.38**
Negative Feelings	0.39**
Social Relationships	-0.56***
Personal Relationships	-0.62***
Social Support	-0.53***
Sexual Activity	-0.11

Note: *** $p < 0.001$; ** $p < 0.01$; the higher the score, the more lonely the respondent

Table 18. Correlations between the Emotional Well-Being scale and its subscales and the WHOQOL-100 global facet and Domain II

WHOQOL-100	Emot.WB	Satisfaction	Activity
Overall Quality of Life and General Health	0.35***	0.34***	0.22**
Psychological Health	0.49***	0.36***	0.42***
Positive Feelings	0.42***	0.30***	0.32***
Thinking, Learning, Memory, & Concentration	0.31***	0.20*	0.36***
Self-esteem	0.47***	0.37***	0.38***
Body Image and Appearance	0.29***	0.21**	0.22**
Negative Feelings	-0.36***	-0.27**	-0.30***

Note: *** $p < 0.001$; ** $p < 0.01$; Emot.WB=Emotional Well-Being

Table 18 shows that Emotional Well-Being was significantly related to the global facet as well as Domain II and all its facets. The lowest correlation was found between Emotional Well-Being and the WHOQOL-100 facet Body Image and Appearance ($r=0.29$) whereas the highest correlation for Emotional Well-being was with WHOQOL-100-Psychological Health at the domain level ($r=0.49$). Concerning the other WHOQOL-100 domains and facets, it appeared that only three domain scores and two facet scores were correlated higher than 0.29 with Emotional Well-Being. These WHOQOL-100 domains were Social Relationships ($r=0.30$; $p<0.001$), Environment ($r=0.37$; $p<0.001$), and Spirituality/Religion/Personal Beliefs ($r=0.31$; $p<0.001$). The two facets were Personal Relationships ($r=0.42$; $p<0.001$) and Participation in and Opportunities for Recreation/Leisure ($r=0.43$; $p<0.001$).

The subscale Satisfaction was linked to the facets of Domain II, the lowest correlation was 0.20 for the WHOQOL-100 facet Thinking, Learning, Memory, and Concentration. In addition, Satisfaction was correlated higher than 0.20 with the WHOQOL-100 domains Social Relationships ($r=0.28$; $p<0.001$), Environment ($r=0.26$; $p<0.01$), and Spirituality/Religion/Personal Beliefs ($r=0.26$; $p<0.01$) and the WHOQOL-100 facets Personal Relationships ($r=0.32$; $p<0.001$), Social Support ($r=0.28$; $p<0.001$), Home Environment ($r=0.21$; $p<0.01$), and Participation in and Opportunities for Recreation/Leisure ($r=-0.28$; $p<0.001$).

Activity was significantly correlated with the entire Domain II and the global facet. This scale was also correlated above 0.22 with the following WHOQOL-100 domains and facets: Physical Health (Domain I; $r=0.26$; $p<0.01$), Environment (Domain V; $r=0.34$; $p<0.001$), Energy and Fatigue ($r=0.32$; $p<0.001$), Sleep and Rest ($r=0.23$; $p<0.01$), Personal Relationships ($r=0.33$; $p<0.001$), Home Environment ($r=0.28$; $p<0.001$), Health and Social Care: Availability and Quality ($r=0.27$; $p<0.01$), Opportunities for Acquiring New Information and Skills ($r=0.26$; $p<0.01$), and Participation in and Opportunities for Recreation/Leisure ($r=-0.40$; $p<0.001$).

Table 19. Correlations between Neighboring, on the one hand, and the WHOQOL-100 global facet and Domain V, on the other hand

WHOQOL-100	Neighboring
Overall Quality of Life and General Health	0.12
Environment	0.27***
Physical Safety and Security	0.29***
Home Environment	0.34***
Financial Resources	0.05
Health and Social Care: Availability and Quality	0.14
Opportunities for Acquiring New Information and Skills	0.01
Participation in and Opportunities for Recreation/Leisure	0.15
Physical Environment	0.28***
Transport	0.18*

Note: *** $p < 0.001$; ** $p < 0.01$

Concerning the Neighboring scale, five significant correlations emerged with the WHOQOL-100 domain V: the facets Transport ($r=0.18$), Physical Environment ($r=0.28$), Physical Safety and Security ($r=0.29$), and Home Environment ($r=0.34$), and with the domain score ($r=0.27$) (see Table 19). Concerning the associations with the other WHOQOL-100 facets and domains, it emerged that the Neighboring scale correlated significantly and above 0.18 with two domain scores, Psychological Health ($r=0.24$; $p<0.01$) and Social Relationships ($r=0.27$; $p<0.01$) and

four facet scores. These facets were Positive Feelings ($r=0.20$; $p<0.05$), Body Image and Appearance ($r=0.32$; $p<0.001$), Personal Relationships ($r=0.27$; $p<0.01$), and Social Support ($r=0.33$; $p<0.001$).

Table 20. Correlations between Residential Satisfaction and WHOQOL-100 Environment

WHOQOL-100	Residential Satisfaction			
	Proximity	Physical Condition	Safety	Gen. Rat.
Overall Quality of Life and General Health	0.08	0.08	0.12	0.08
Environment	-0.08	-0.15	0.23**	0.21**
Physical Safety and Security	-0.09	0.19*	0.36***	0.34***
Home Environment	-0.09	0.14	0.29***	0.38***
Financial Resources	-0.01	0.11	0.12	0.02
Health and Social Care: Availability and Quality	0.20*	-0.04	0.08	-0.03
Opportunities for Acquiring New Information and Skills	0.11	0.02	0.01	-0.05
Participation in and Opportunities for Recreation/Leisure	-0.13	-0.08	0.03	0.03
Physical Environment (pollution/noise/traffic/climate)	-0.06	0.26**	0.35***	0.33***
Transport	0.17*	0.15*	0.06	0.08

Note: *** $p < 0.001$; ** $p < 0.01$; Gen.Rat.=General Rating of Home Environment and Satisfaction with the House

In Table 20 the correlations between the four Residential Satisfaction scales and Domain V (Environment) are shown. It appeared that Proximity was only significantly related to Health and Social Care: Availability and Quality and Transport. Looking at the other WHOQOL-100 domains and facets, only three significant correlations were found with Proximity: Body Image and Appearance ($r=0.18$; $p<0.05$), Activities of Daily Living ($r=0.17$; $p<0.05$), and Sexual Activity ($r=-0.17$; $p<0.05$). The scale Physical Condition was significantly related to the WHOQOL-100 facets Transport ($r=0.15$), Physical Safety and Security ($r=0.19$), and Physical Environment ($r=0.26$) and not with any other facet of the WHOQOL-100. Safety and General Rating of Home Environment and Satisfaction with the House were both significantly correlated with the WHOQOL-100 facets Physical Safety and Security, Home Environment, and Physical Environment. In addition, these last two Residential Satisfaction scales were also significantly related to the domain score of Domain V. Finally, whereas Safety was not related to any of the other WHOQOL-100 domains and facets, General Rating of Home Environment and Satisfaction with the House was significantly correlated with the facets Energy and Fatigue and Body Image and Appearance

($r=0.21$; $p<0.01$ in both cases) and the domain Spirituality/Religion/Personal Beliefs ($r=0.16$; $p<0.05$).

Norms

A first indication of average scores that elderly persons will receive on the facets and domains of the WHOQOL-100 is presented in Table 21.

Table 21. Average scores and standard deviations of the elderly

WHOQOL-100	Mean score	SD
Overall Quality of Life and General Health	15.6	2.6
Physical Health	14.5	2.6
Pain and Discomfort	10.3	3.2
Energy and Fatigue	14.5	3.0
Sleep and Rest	15.2	3.7
Psychological Health	14.9	1.8
Positive Feelings	14.0	2.2
Thinking, Learning, Memory, & Concentration	14.6	2.2
Self-esteem	14.5	2.1
Body Image and Appearance	17.0	2.8
Negative Feelings	9.4	3.0
Level of Independence	15.4	2.8
Mobility	15.3	3.2
Activities of Daily Living	15.8	3.1
Dependence on Medication or Treatments	8.9	3.3
Working Capacity	15.5	3.3
Social Relationships	15.3	2.3
Personal Relationships	16.1	2.6
Social Support	15.8	3.1
Sexual Activity	14.0	3.8
Environment	15.7	1.7
Physical Safety and Security	15.5	2.4
Home Environment	15.7	2.5
Financial Resources	16.4	3.1
Health and Social Care: Availability and Quality	15.7	2.4
Opportunities for Acquiring New Information and Skills	14.98	2.5
Participation in and Opportunities for Recreation/Leisure	15.17	2.9
Physical Environment (pollution/noise/traffic/climate)	14.99	2.4
Transport	16.91	3.2
Spirituality/Religion/Personal Beliefs	13.70	3.5

6.4 Study 4: The sarcoidosis study³

In the fourth study, a group of sarcoidosis patients completed a number of questionnaires such as the WHOQOL-100, the SIP and the BDI. Sarcoidosis is a multisystemic disorder with the lung being the most frequently involved organ. Sarcoidosis patients have at least one scar on their lungs and the cause of that scar is unknown. Depending on the organs involved, symptoms range from cough and dyspnoea to joint and muscle pain. The data from this study was used to further validate the WHOQOL-100. The results will be presented below.

6.4.1 Method

Subjects

The respondents, who all suffered from sarcoidosis, were recruited in seven hospitals in the South of The Netherlands. Persons who were between 18 and 75 years of age were asked to participate in a study unless they were pregnant or did have a maligna or any disability due to another serious disease or psychiatric disorder. Moreover, patients were not asked to participate in the case that they were incapable to complete questionnaires. The present study was part of a larger study into the QoL of these patients.

The age of the respondents ($N=64$) ranged from 25 to 73 ($M=42.7$; $SD=11.9$). The group of respondents consisted of slightly more men (57.8%).

Measures

In this study, two generic measures, the WHOQOL-100 and the Sickness Impact Profile (SIP; Bergner *et al.*, 1981), as well as one disease-specific measure and two domain-specific measures were employed.

The SIP is a health status measure that was developed to assess the restraints on behavior caused by illness. Therefore, it measures the extent of dysfunctions in terms of behavioral changes that restrict normal daily activities (König-Zahn *et al.*, 1993). This instrument was chosen because, as mentioned in Chapter 1, it is often used as a measure of QoL. Furthermore, the validity and reliability of this measure appear to be good (e.g., Bergner *et al.*, 1981; Bowling, 1995; König-Zahn *et al.*, 1993). In the present study, the category Communication was not included in the analyses because for only 11 respondents a score on this part of the SIP could be obtained.

³ I would like to thank Mrs. Dr. M. Drent, pulmonary physician, Dr. M.H.M. Breteler, clinical psychologist, and the staff of the following hospitals for collecting the data: Rijnstate Hospital, Arnhem; Sint Radboud Hospital, Nijmegen; Rehabilitation Centre Dekkerswald, Nijmegen; Sint Jans-Gasthuis, Weert; Maasland Hospital, Sittard; The Wever Hospital, Heerlen; University Hospital, Maastricht.

The Medical Psychological Questionnaire for CARA patients (MPVC; Erdman *et al.*, 1992a) is a 52-item disease-specific instrument for persons with a lung disease. This instrument consists of the four scales Well-Being, Feeling of being Disabled, Displeasure, and Social Inhibition. The reliability and validity of the MPVC seems to be good (Erdman, Cox, & Duivenvoorden, 1992b).

The domain-specific measures were the Beck Depression Inventory (BDI; Beck *et al.*, 1961) and the Positive and Negative Affect Schedule (PANAS; Watson *et al.*, 1988). Both measures were used to validate the Psychological Health domain.

The BDI is a 21-item measure which was developed to assess clinical depression. It is a very popular questionnaire which is used in all kinds of studies (e.g., Arasteh, 1994; Dalack *et al.*, 1995; Goodale & Stoner, 1994; Heebink, Sunday, & Halmi, 1995; Kok *et al.*, 1995). This measure has good reliability and validity (*cf.* Bowling, 1995).

The PANAS measures two relatively independent affects, namely positive affect (PA) and negative affect (NA). It consists of 20 terms that describe different feelings and emotions, 10 terms for PA and 10 terms for NA. The reliability and validity of these two scales appear to be good (Watson *et al.*, 1988).

6.4.2 Results

Reliability

As in the other studies, first, the reliability (internal consistency) of the WHOQOL-100 was calculated. Again, it appeared that the reliability of the instrument was very good. The internal consistency of the facets ranged from 0.69 for Health and Social Care: Availability and Quality to 0.94 for Working Capacity. The range for the domains went from 0.78 for Physical Health to 0.90 for Psychological Health (see Table 22).

Construct validity

The construct validity of the WHOQOL-100 was studied by correlating the SIP, MPVC, BDI, and PANAS with the WHOQOL-100 domains and facets.

In Table 23, the relationship between the categories of the SIP and the WHOQOL-100 facets are shown. It appeared that SIP-Ambulation and SIP-Mobility were correlated highest with the WHOQOL-100 facet Mobility (Facet 9). The SIP category Ambulation also correlated highly with the WHOQOL-100 facets Activities of Daily Living (Facet 10), Working Capacity (Facet 12), and Participation in and Opportunities for Recreation/Leisure (Facet 21), whereas SIP-Mobility also correlated substantially with the WHOQOL-100 facets Participation in and Opportunities for

Recreation/Leisure (Facet 21), Thinking, Learning, Memory, and Concentration (Facet 5), and Working Capacity. Furthermore, SIP-Body Care and Movement correlated highest with the WHOQOL-100 facets Mobility (Facet 9), followed by Working Capacity (Facet 12), and Activities of Daily Living (Facet 10). Concerning SIP-Social Interaction, all facets of the WHOQOL-100 domains Psychological Health, Level of Independence, and Social Relationships (Facet 4 to Facet 15) were related significantly with this SIP category. The highest correlation was found with Thinking, Learning, Memory, and Concentration (Facet 5; $r=-0.64$) and Participation in and Opportunities for Recreation/Leisure (Facet 21; $r=-0.62$). SIP-Alertness Behavior correlated very high with the WHOQOL-100 facet Thinking, Learning, Memory, and Concentration ($r=-0.73$). Finally, SIP-Emotional Behavior correlated highest with the WHOQOL-100 facet Negative Feelings (Facet 8; $r=0.65$), followed by the facet Self-Esteem (Facet 6; $r=-0.63$).

Table 22. Internal consistency of the WHOQOL-100 among sarcoidose patients

WHOQOL scales	Cronbach's alpha
Facet 0: Overall Quality of Life and General Health	0.90
Domain I: Physical Health	0.78
Facet 1: Pain and Discomfort	0.82
Facet 2: Energy and Fatigue	0.92
Facet 3: Sleep and Rest	0.91
Domain II: Psychological Health	0.90
Facet 4: Positive Feelings	0.88
Facet 5: Thinking, Learning, Memory, and Concentration	0.89
Facet 6: Self-Esteem	0.87
Facet 7: Body Image and Appearance	0.88
Facet 8: Negative Feelings	0.86
Domain III: Level of Independence	0.89
Facet 9: Mobility	0.85
Facet 10: Activities of Daily Living	0.92
Facet 11: Dependence on Medication or Treatments	0.88
Facet 12: Working Capacity	0.94
Domain IV: Social Relationships	0.82
Facet 13: Personal Relationships	0.80
Facet 14: Social Support	0.88
Facet 15: Sexual Activity	0.90
Domain V: Environment	0.87
Facet 16: Physical Safety and Security	0.81
Facet 17: Home Environment	0.85
Facet 18: Financial Resources	0.84
Facet 19: Health and Social Care: Availability and Quality	0.69
Facet 20: Opportunities for Acquiring New Information and Skills	0.77
Facet 21: Participation in and Opportunities for Recreation/Leisure	0.87
Facet 22: Physical Environment (pollution/noise/traffic/climate)	0.77
Facet 23: Transport	0.79
Domain VI: Spirituality/Religion/Personal Beliefs	0.88

Although SIP-Sleep and Rest correlated -0.44 with the WHOQOL-100 facet Sleep and Rest (Facet 3), this SIP category correlated higher with Working Capacity (Facet 12), Activities of Daily Living (Facet 10), and Mobility (Facet 9). The highest correlation for SIP-Eating was found with Physical Environment (Facet 22). SIP-Work was correlated 0.60 with the WHOQOL-100 facet Dependence on Medication or Treatments (Facet 11) and -0.54 with WHOQOL-100-Working Capacity (Facet 12). Finally, the SIP categories Home Management and Recreation and Pastimes were correlated quite high with the WHOQOL-100 facets Mobility (Facet 9; $r=-0.69$ and $r=-0.59$, respectively), Activities of Daily Living (Facet 10; $r=-0.68$ and $r=-0.58$, respectively), Participation in and Opportunities for Recreation/Leisure (Facet 21; $r=-0.67$ and $r=-0.51$, respectively), and Working Capacity (Facet 12; $r=-0.66$ and $r=-0.57$, respectively).

Table 23. Correlations between the WHOQOL-facets and the SIP-scales¹

	SIP										
	Amb.	Mob.	BCM	SI	AB	EB	SR	Eat.	Work	HM	RP
Facet 0	-0.12	-0.04	0.01	-0.03	0.11	0.13	0.08	0.13	0.01	-0.06	-0.00
Facet 1	0.21	0.20	0.10	0.21	0.16	0.01	-0.09	0.13	0.07	0.17	0.14
Facet 2	-0.15	-0.21	-0.20	-0.03	-0.08	0.14	0.01	-0.15	-0.06	-0.13	0.01
Facet 3	-0.24	-0.20	-0.34**	-0.20	-0.25*	-0.34**	-0.44***	-0.35**	-0.20	-0.34**	-0.39**
Facet 4	-0.47***	-0.53***	-0.27*	-0.50***	-0.40**	-0.51***	-0.24	-0.48***	-0.36**	-0.49***	-0.36**
Facet 5	-0.49***	-0.58***	-0.36**	-0.64***	-0.73***	-0.53***	-0.30*	-0.47***	-0.41**	-0.56***	-0.51***
Facet 6	-0.49***	-0.50***	-0.34**	-0.51***	-0.51***	-0.63***	-0.30*	-0.50***	-0.34**	-0.51***	-0.48***
Facet 7	-0.44***	-0.43***	-0.26*	-0.35**	-0.36**	-0.55***	-0.16	-0.27*	-0.35**	-0.36**	-0.41**
Facet 8	0.36**	0.30*	0.24	0.45***	0.41**	0.65***	0.28*	0.41**	0.42**	0.47***	0.42**
Facet 9	-0.71***	-0.62***	-0.73***	-0.49***	-0.36**	-0.55***	-0.48***	-0.51***	-0.37**	-0.69***	-0.59***
Facet 10	-0.63***	-0.51***	-0.56***	-0.53***	-0.52***	-0.53***	-0.56***	-0.48***	-0.46***	-0.68***	-0.58***
Facet 11	0.54***	0.46***	0.40**	0.46***	0.34**	0.46***	0.33**	0.30*	0.60***	0.53***	0.50***
Facet 12	-0.63***	-0.58***	-0.60***	-0.50***	-0.48***	-0.49***	-0.60***	-0.50***	-0.54***	-0.66***	-0.57***
Facet 13	-0.41**	-0.41**	-0.23	-0.51***	-0.37**	-0.51***	-0.18	-0.42**	-0.26*	-0.41**	-0.43***
Facet 14	-0.51***	-0.40**	-0.24	-0.46***	-0.29*	-0.33**	-0.16	-0.48***	-0.30*	-0.39**	-0.39**
Facet 15	-0.45***	-0.36**	-0.11	-0.49***	-0.23	-0.45***	-0.02	-0.11	-0.35**	-0.41**	-0.41**
Facet 16	-0.39**	-0.29*	-0.36**	-0.35**	-0.39**	-0.44***	-0.20	-0.29*	-0.32**	-0.41**	-0.38**
Facet 17	-0.24	-0.39**	-0.29*	-0.27*	-0.29*	-0.44***	-0.36**	-0.47***	-0.22	-0.30*	-0.24
Facet 18	-0.26*	-0.35**	-0.41**	-0.13	-0.39**	-0.16	-0.17	-0.38**	-0.30*	-0.38**	-0.16
Facet 19	-0.36**	-0.24	-0.14	-0.29*	-0.16	-0.30*	-0.25	-0.27*	-0.34**	-0.34**	-0.27*
Facet 20	-0.43***	-0.43***	-0.35**	-0.37**	-0.45***	-0.52***	-0.37**	-0.35**	-0.35**	-0.46***	-0.33**
Facet 21	-0.63***	-0.60***	-0.43***	-0.62***	-0.59***	-0.52***	-0.41**	-0.47***	-0.36**	-0.67***	-0.51***
Facet 22	-0.40**	-0.46***	-0.40**	-0.41**	-0.28*	-0.48***	-0.28*	-0.55***	-0.32**	-0.39**	-0.36**
Facet 23	-0.42**	-0.52***	-0.49***	-0.28*	-0.32*	-0.29*	-0.08	-0.35**	-0.20	-0.47***	-0.21

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; Amb.=Ambulation; Mob.=Mobility; BCM=Body Care and Movement; SI=Social Interaction, AB=Alertness Behavior; EB=Emotional Behavior; SR=Sleep and Rest; Eat.=Eating; HM=Home Management; RP=Recreation and Pastimes. ¹ A high score on the WHOQOL-100, means a high level of functioning. In contrast, a high score on the SIP, means a high level of dysfunctioning.

Subsequently, the SIP-Physical Functioning Domain score and the SIP-Psychosocial Functioning Domain were calculated. SIP-Physical Domain consisted of the scales Ambulation, Body Care and Movement, and Mobility. Psychosocial Functioning was calculated on the basis of three scales: Emotional Behavior, Social Interaction, and Alertness Behavior. Then, the relationship between these domain scores and the six domains of the WHOQOL-100 were calculated. The results are presented in Table 24. It appeared that the two SIP domains were significantly correlated with five out of the six WHOQOL-100 domains. The strongest links for the SIP-Psychosocial dimension were found with the WHOQOL-100 domains Psychological Health ($r=-0.71$) and Level of Independence ($r=-0.62$). SIP-Physical dimension was related strongest with Level of Independence ($r=-0.75$) and Environment ($r=-0.62$). Physical Health was not related to the SIP domains (see Table 24).

Table 24. Correlations between the domains of the WHOQOL-100 and the SIP

	SIP-Physical dimension	SIP-Psychosocial dimension
Physical Health	-0.20	-0.06
Psychological Health	-0.54***	-0.71***
Level of Independence	-0.75***	-0.62***
Social Relationships	-0.41**	-0.54***
Environment	-0.62***	-0.57***
Spirituality/Religion/Personal Beliefs	-0.37**	-0.39**

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

Looking at Table 25, it appears that none of the MPVC scales was significantly related to the WHOQOL-100 facets Overall Quality of Life and General Health (Facet 0), Pain and Discomfort (Facet 1), and Energy and Fatigue (Facet 2). In addition, no significant relationship was found with the WHOQOL-100 domain Physical Health (Domain I).

The MPVC scale Well-Being had its highest correlation with the WHOQOL-100 domains Psychological Health (Domain II) and Level of Independence (Domain III). At the facet level the highest correlations for MPVC-Well-Being was found with the WHOQOL-100 facet Activities of Daily Living (Facet 10), followed by the facets Participation in and Opportunities for Recreation /Leisure (Facet 21; $r=0.75$) and Working Capacity (Facet 12; $r=0.74$). MPVC-Feeling of Being Disabled correlated -0.78 with the WHOQOL-100 domain Level of Independence (Domain III) and -0.75 with the WHOQOL-100 facet Working Capacity (Facet 12). The MPVC scale Displeasure was significantly related to the WHOQOL-100 domains Psychological Health (Domain II), Level of Independence (Domain III), and Spirituality/Religion/Personal Beliefs (Domain VI). Furthermore, MPVC-Displeasure was significantly correlated with all five facets belonging to

Physical Health (Domain I) as well as with the facets Mobility (Facet 9), Activities of Daily Living (Facet 10), and Working Capacity (Facet 12) of Level of Independence, and Personal Relationships (Facet 13) of Social Relationships. The highest significant correlation ($r=-0.40$) was with the WHOQOL-100 facets Thinking, Learning, Memory, and Concentration (Facet 5) and Self-Esteem (Facet 6).

Table 25. Correlations between the BDI, the scales of the MPVC, and the scales of the PANAS on the one hand and the WHOQOL-100 domains and facets on the other hand

WHOQOL-100	MPVC				BDI	PANAS	
	W-B	FD	D	SI		PA	NA
Facet 0	-0.11	0.02	0.18	0.22	-0.04	0.02	0.14
Domain I	0.06	-0.06	-0.10	0.03	0.05	0.18	0.17
Facet 1	-0.08	0.09	0.00	0.08	0.03	-0.25	-0.01
Facet 2	-0.00	-0.05	0.13	0.01	0.02	0.14	0.18
Facet 3	0.41**	-0.44***	-0.00	-0.24	0.40**	0.06	-0.42**
Domain II	0.75***	-0.69***	-0.44***	-0.48***	-0.65***	0.56***	-0.69***
Facet 4	0.71***	-0.64***	-0.38**	-0.34**	-0.51***	0.63***	-0.45***
Facet 5	0.60***	-0.58***	-0.40***	-0.40***	-0.53***	0.53***	-0.51***
Facet 6	0.65***	-0.58***	-0.40***	-0.44***	-0.57***	0.56***	-0.57***
Facet 7	0.43***	-0.40**	-0.26*	-0.36**	-0.48***	0.25	-0.54***
Facet 8	-0.71***	0.62***	0.36**	0.43***	0.50***	-0.35**	0.72***
Domain III	0.75***	-0.78***	-0.31*	-0.24	-0.72***	0.39**	-0.61***
Facet 9	0.59***	-0.66***	-0.26*	-0.13	-0.59***	0.38**	-0.47***
Facet 10	0.78***	-0.76***	-0.30*	-0.24	-0.73***	0.40**	-0.60***
Facet 11	-0.53***	0.59***	0.17	0.19	0.52***	-0.14	0.55***
Facet 12	0.74***	-0.75***	-0.35**	-0.27*	-0.70***	0.47***	-0.53***
Domain IV	0.58***	-0.58***	-0.16	-0.20	-0.48***	0.43***	-0.47***
Facet 13	0.58***	-0.52***	-0.27*	-0.26*	-0.50***	0.49***	-0.49***
Facet 14	0.59***	-0.54***	-0.16	-0.23	-0.37**	0.44***	-0.37**
Facet 15	0.39**	-0.47***	-0.00	-0.04	-0.41***	0.24	-0.43***
Domain V	0.67***	-0.63***	-0.18	-0.38**	-0.52***	0.43***	-0.49***
Facet 16	0.50***	-0.40**	-0.05	-0.27*	-0.43***	0.17	-0.48***
Facet 17	0.42***	-0.41**	-0.20	-0.19	-0.52***	0.28*	-0.39**
Facet 18	0.35**	-0.30*	-0.00	-0.33**	-0.11	0.08	-0.17
Facet 19	0.48***	-0.43***	-0.11	-0.10	-0.29*	0.27*	-0.30*
Facet 20	0.51***	-0.48***	-0.22	-0.24	-0.43***	0.18	-0.49***
Facet 21	0.75***	-0.67***	-0.23	-0.31*	-0.56***	0.55***	-0.48***
Facet 22	0.46***	-0.48***	-0.22	-0.34**	-0.41**	0.41**	-0.34**
Facet 23	0.39**	-0.46***	-0.15	-0.36**	-0.21	0.46***	-0.17
Domain VI	0.44***	-0.36**	-0.28*	-0.25*	-0.34**	0.39**	-0.38**

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; W-B=Well-Being; FD=Feeling of being Disabled; D=Displeasure; SI=Social Inhibition.

MPVC-Displeasure was not related to Domain V (Environment). Finally, the MPVC scale Social Inhibition correlated highest with the WHOQOL-100 domain Psychological Health (Domain II). Looking at the WHOQOL-100 facet level, it appeared that MPVC-Social Inhibition correlated highly with all facets of WHOQOL-100 Domain II. There were only two WHOQOL-100 facets

from Domain V (Environment) - Physical Environment (pollution/noise/traffic/climate) and Transport - that correlated at least as high with MPVC-Social Inhibition as the WHOQOL-100 facets from Domain II (see Table 25).

The BDI correlated highest with the WHOQOL-100 Level of Independence (Domain III) and Psychological Health (Domain II): -0.72 and -0.65, respectively. There was no significant link with Physical Health (Domain I). At the facet level, it emerged that three WHOQOL-100 facets belonging to Domain III - Activities of Daily Living, Working Capacity, and Mobility - had the highest correlations with the BDI. The relationship with the facets from Domain II was also quite high, with correlations ranging from -0.48 (Facet 7: Bodily Image and Appearance) to -0.57 (Body 6: Self-Esteem) and 0.50 (Facet 8: Negative Feelings). There were only five WHOQOL-100 facets that were not related to the BDI. Among these facets were two out of the three facets belonging to Domain I and the global facet Overall Quality of Life and General Health (see Table 25).

Both PA and NA were associated strongest with the WHOQOL-100 domain Psychological Health (Domain II), with correlations of 0.56 and -0.69, respectively. PA had the highest correlation ($r=0.63$) with the WHOQOL-100 facet Positive Feelings (Facet 4) and the lowest ($r=0.02$) with WHOQOL-100 Overall Quality of Life and General Health. NA correlated highest ($r=0.72$) with Negative Feelings (Facet 8) and lowest ($r=-0.01$) with Pain and Discomfort (Facet 1). Just like the BDI, PA and NA were not related to the WHOQOL-100 domain Physical Health (Domain I). Furthermore, the PANAS scales were unrelated to the WHOQOL-100 facets Overall Quality of Life and General Health (Facet 0), Pain and Discomfort (Facet 1), Energy and Fatigue (Facet 2), and Financial Resources (Facet 18). In addition, PA was also unrelated to Sleep and Rest (Facet 3), Bodily Image and Appearance (Facet 7), Dependence on Medication or Treatment (Facet 11), Sexual Activity (Facet 15), Physical Safety and Security (Facet 16), and Opportunities for Acquiring New Information and Skills (Facet 20). Finally, NA was not significantly correlated with Transport (Facet 23; see Table 25).

Norms

As in the other studies, the average scores and standard deviations were calculated for the present lung patients (see Table 26). These scores are a first indication for the norms for persons suffering from a lung disease.

Table 26. Average scores and standard deviations of the sarcoidosis patients

WHOQOL-100	Mean score	SD
Overall Quality of Life and General Health	12.1	4.1
Physical Health	13.2	1.3
Pain and Discomfort	12.1	4.1
Energy and Fatigue	12.1	4.1
Sleep and Rest	15.6	3.8
Psychological Health	15.2	2.5
Positive Feelings	14.7	2.9
Thinking, Learning, Memory, & Concentration	15.0	3.4
Self-esteem	14.5	2.8
Body Image and Appearance	16.6	3.1
Negative Feelings	8.5	3.1
Level of Independence	15.3	3.4
Mobility	16.6	3.2
Activities of Daily Living	14.9	3.9
Dependence on Medication or Treatments	8.6	4.1
Working Capacity	14.5	4.4
Social Relationships	16.0	2.8
Personal Relationships	16.3	3.0
Social Support	16.2	3.4
Sexual Activity	15.5	3.4
Environment	16.1	2.1
Physical Safety and Security	16.3	2.8
Home Environment	16.3	3.0
Financial Resources	16.8	2.8
Health and Social Care: Availability and Quality	15.5	2.4
Opportunities for Acquiring New Information and Skills	15.8	2.7
Participation in and Opportunities for Recreation/Leisure	15.4	3.6
Physical Environment (pollution/noise/traffic/climate)	15.2	2.8
Transport	17.9	3.0
Spirituality/Religion/Personal Beliefs	13.1	3.5

6.5 Study 5: The psoriasis study⁴

Psoriasis is a chronic skin disease that may affect any region of the skin and has an irregular course (Dungey & Buselmeier, 1982). In general, the rash is a silvery scale, which is characterized by extreme thickening, constant shedding and cracking of the skin. Sometimes the disease also causes itching, ulceration, and infection of the skin (Dungey & Buselmeier, 1982; Kerr, 1992). The illness can reveal itself at any age but usually between the age of 20 and 40 (Kerr, 1992). In many cases, the disease starts after a period of stress and the patients will have the disease for the rest of their lives. Stress very often also proceeds psoriasis attacks (Gupta, Gupta,

⁴I would like to thank Femke Mombers and Els de Bakker for collecting the data.

& Haberman, 1987). Prevalence is 1 to 2 percent in the general population, distributed equally between men and women (Buchheim & Elhardt-Ringsgwandl, 1992; Dungey & Buselmeier, 1982; Gupta *et al.*, 1987).

The department of skin disease of the academic hospital of Nijmegen University started two clinical trials for testing new medication with psoriasis patients at the beginning of 1996. Within the context of these clinical trials, the patients completed the WHOQOL-100 when they entered the trials. The aim of this part of the study was to investigate the reliability and the criterion and construct validity of the WHOQOL-100.

6.5.1 Method

Subjects

The subjects were 41 psoriasis patients who visited their dermatologist at the St. Radboud Hospital in The Netherlands. Patients were invited to participate when they had a severity score of at least 5. Patients ranged in age from 24 to 78 years ($M = 49.7$, $SD = 12.4$). Thirty-seven persons were living together with a partner. Average age of onset of the illness was 25.9 years ($SD = 12.2$), with ages ranging from 10 years to 68 years.

Measures

In this study, besides a part of the WHOQOL-100, the following three questionnaires were employed: the Psoriasis Disability Index (PDI; Finlay & Coles, 1995), the Ben-Tovim Walker Body Attitudes Questionnaire (BAQ; Ben-Tovim & Walker, 1991, 1992), and the Short Form of the Social Support Questionnaire (SSQ-SF; Sarason, Sarason, Shearin, & Pierce, 1987).

Concerning the WHOQOL-100, in the present study, only 12 facets were used in order to reduce the load for the patients. These facets were Overall Quality of Life and General Health, Pain and Discomfort, Energy and Fatigue, Sleep and Rest, Positive Feelings, Self-Esteem, Body Image and Appearance, Negative Feelings, Dependence on Medication or Treatments, Personal Relationships, Social Support, and Sexual Activity.

The PDI is a disease-specific health status measure that was developed especially for psoriasis patients and measures four aspects of disability, namely Daily Activities, Personal Relationships, Leisure Time, and Treatment. According to Finlay and Coles (1995), the overall score reflects the impact that psoriasis had on the patients during the previous month. It was validated against the SIP. In the present study, the items "How much has your psoriasis made you lose time off work over the last 4 weeks?", "How much has your psoriasis prevented you from doing things at work over the last 4 weeks?", "How much has your psoriasis stopped you carrying out your normal

daily activities over the last 4 weeks?", and "How much has your psoriasis altered the way in which you carry out your normal daily activities over the last 4 weeks?" were not included in the overall score because at least 12 persons indicated that the first two items were not applicable to them. Concerning the last two items, at least 16 persons had not replied to these questions. The reliability of the remaining 13-item total PDI scale was 0.84.

The BAQ measures persons' attitudes towards their body. The original scale contains a number of items that particularly refer to the respondents body size. In the present study, only those questions that did not refer explicitly to body size but were framed more broadly, were used. In this study, the BAQ consisted of 11 questions, 6 items belonging to the subscale Body Disparagement (internal consistency 0.73) and 5 items belonging to the subscale Attractiveness (internal consistency 0.74). The reliability of the total BAQ score was 0.81. The BAQ was especially used to validate the WHOQOL-100 facet Body Image and Appearance.

The SSQ-SF, which consists of six items, was used to validate the WHOQOL-100 domain Social Relationships. Like the SSQ, the SSQ-SF measures two aspects of social support which also yields two scores. First, the respondent has to identify the number of people that one "can count on" for support. Second, the respondent has to evaluate this support by giving a global rating of satisfaction concerning the availability of the social network (e.g., Sarason *et al.*, 1983). The SSQ-SF appears to have a good reliability and validity. In the present study, the internal consistency was 0.93 for the satisfaction aspect.

The severity of the psoriasis is assessed by dermatologists using the Psoriasis Area and Severity Index (PASI; Fleischer, Rapp, Reboussin, Vanarthos, & Feldman, 1994), which determines the erythema, duration, desquamation and the area of the trunk, head, upper extremities and lower extremities of the body which are effected. This measure is completed by dermatologists. This measure consists of a semi quantitative score for erythema, desquamation, induration, and area, with a weighting factor for the extent to which the disease is spread within each skin area. In the present study, the scores on this index ranged from 5.0 to 24.0 ($M=11.5$; $SD=5.5$).

6.5.2 Results

Reliability

The WHOQOL-100 domains and facets that were used in this study all appeared to have a good internal consistency. The alpha's for the facets ranged from 0.67 for Self-Esteem to 0.94 for Sleep and Rest. Concerning the domains, the reliability was 0.64 for Physical Health, 0.69 for Psychological Health, and 0.72 for Social Relationships (see Table 27).

Table 27. Internal consistency of the WHOQOL-100 among psoriasis patients

WHOQOL scales	Cronbach's alpha
Overall Quality of Life and General Health	0.78
Domain I: Physical Health	0.64
Pain and Discomfort	0.76
Energy and Fatigue	0.78
Sleep and Rest	0.94
Domain II: Psychological Health	0.69
Positive Feelings	0.82
Self-Esteem	0.67
Body Image and Appearance	0.90
Negative Feelings	0.83
Domain III: Level of Independence	
Dependence on Medication or Treatments	0.81
Domain IV: Social Relationships	0.72
Personal Relationships	0.81
Social Support	0.81
Sexual Activity	0.87

Construct validity

In order to establish the construct validity of the WHOQOL-100, this instrument was correlated with the PDI, the BAQ, and the SSQ-SF (see Table 28). Concerning the relationship between the PDI and the WHOQOL-100, it appeared that the PDI was related to the WHOQOL-100 facets Overall Quality of Life and General Health ($r=-0.46$), Pain and Discomfort ($r=0.52$), Body Image and Appearance ($r=-0.51$), Negative Feelings ($r=0.41$), Dependence on Medication or Treatments ($r=0.60$), and Personal Relationships ($r=-0.47$). In addition, the PDI was significantly correlated with all the WHOQOL-100 domains that were measured, being Physical Health ($r=-0.38$), Psychological Health ($r=-0.50$), and Social Relationships ($r=-0.42$).

The total BAQ score was correlated significantly with the WHOQOL-100 facet Body Image and Appearance ($r=0.64$). In addition, the total BAQ score was significantly associated with WHOQOL-100-Negative Feelings ($r=-0.41$) and WHOQOL-100-Dependence on Medication or Treatments ($r=-0.48$), and the WHOQOL-100 domain score Psychological Health ($r=0.47$). With respect to the two subscales of the BAQ, Attractiveness and Body Disparagement, the same significant correlations were found. In addition, it appeared that BAQ-Attractiveness was associated with the global WHOQOL-100 facet Overall Quality of Life and General Health ($r=0.32$) as well as the WHOQOL-100 facet Personal Relationships ($r=0.37$).

Table 28. Correlations between (i) the WHOQOL-100 and (ii) the PDI, BAQ, and SSQ-SF

WHOQOL-100	PDI	BAQ	BAQ-BD	BAQ-A	SSQ-SF-Sat.	PASI
Overall Quality of Life a. nd						
General Health	-0.46**	0.18	0.03	0.32*	0.27	-0.24
Physical Health	-0.38*	0.22	0.17	0.22	0.41*	-0.13
Pain and Discomfort	0.52**	-0.26	-0.21	-0.23	-0.25	0.02
Energy and Fatigue	-0.22	0.05	0.01	0.08	0.34*	-0.09
Sleep and Rest	-0.21	0.19	0.16	0.18	0.35*	-0.17
Psychological Health	-0.50**	0.47**	0.33*	0.50**	0.38*	-0.28
Positive Feelings	0.32	0.05	0.01	0.10	0.45**	-0.03
Self-esteem	-0.15	0.08	-0.04	0.19	0.20	-0.10
Body Image and Appearance	-0.51**	0.64***	0.47**	0.65***	0.15	-0.46**
Negative Feelings	0.41*	-0.41**	-0.35*	-0.37*	-0.35*	0.12
Level of Independence						
Dependence on Medication or Treatments	0.60***	-0.48**	-0.47**	-0.35*	-0.16	0.38*
Social Relationships	-0.42*	0.21	0.13	0.24	0.33	-0.08
Personal Relationships	-0.47**	0.23	0.06	0.37*	0.29	-0.21
Social Support	-0.25	0.26	0.25	0.20	0.07	-0.01
Sexual Activity	-0.33	0.02	-0.02	0.06	0.39*	-0.00

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; BAQ=total BAQ score; BAQ-BD=BAQ-body Disparagement; BAQ-A=BAQ-Attractiveness; SSQ-SF-Sat.=SSQ-SF-Satisfaction; PASI=measure for psoriasis severity

Finally, the relationship between WHOQOL-100 and SSQ-SF-Satisfaction was reviewed. It appeared that the SSQ-SF-Satisfaction was significantly correlated with the WHOQOL-100 domain scores Physical Health ($r=0.41$) and Psychological Health ($r=0.38$). Furthermore, the SSQ-SF scale was related to the WHOQOL-100 facets Energy and Fatigue ($r=0.34$), Sleep and Rest ($r=0.35$), Positive Feelings ($r=0.45$), Negative Feelings ($r=-0.35$), and Sexual Activity ($r=0.39$).

Criterion validity

Subsequently, in order to investigate whether there was a relation between the severity of psoriasis and QoL, the PASI score was correlated with the facets and domains of the WHOQOL-100. It appeared that the PASI score was only significantly related to the WHOQOL-100 facets Dependence on Medication or Treatment ($r=0.38$) and Body Image and Appearance ($r=-0.46$; see Table 28).

Norms

In Table 29 the mean scores and standard deviations of the present psoriasis population are presented. This is merely a first indication scores that psoriasis patients will receive on the WHOQOL-100 domains and facets.

Table 29. Average scores and standard deviations of psoriasis patients

WHOQOL-100	Mean score	SD
Overall Quality of Life and General Health	15.2	2.8
Physical Health	14.7	2.6
Pain and Discomfort	10.1	3.0
Energy and Fatigue	14.8	2.9
Sleep and Rest	15.3	4.1
Psychological Health	14.1	2.1
Positive Feelings	14.2	2.6
Self-esteem	14.5	2.0
Body Image and Appearance	14.0	3.7
Negative Feelings	10.2	3.0
Dependence on Medication and/or Treatments	9.2	3.9
Social Relationships	15.1	2.7
Personal Relationships	16.4	3.1
Social Support	15.3	3.4
Sexual Activity	13.9	3.7

6.6 Study 6: The rheumatoid arthritis study

The disease rheumatoid arthritis (RA) is characterized by complaints that are centred in and/or around the joints (see, e.g., Taal, Seydel, & Wiegman, 1988). In addition, it is a chronic disease which means that one has to adapt to it (Dickhaut, 1980). The major disease-related complaints of RA are pain, fatigue, and morning stiffness (Bal, 1992; De Witte *et al.*, 1989).

The prevalence of RA is 1 to 2 percent, with the majority of the patients being women. The disease usually starts after the age of 50 years.

6.6.1 Method

Subjects

An advertisement was placed in the magazine of the local rheumatic diseases patient organization. Twelve persons indicated that they were willing to complete a test-booklet every evening for ten days. Eight respondents were women and the ages ranged from 28 to 75 ($M=56.2$; $SD=15.2$).

Furthermore, nine persons were living together with a partner and 75 percent only had a low education level.

Measures

At day 1, the test-booklet consisted of the WHOQOL-100, the RAND-36 (Ware, 1993; Dutch version by Van der Zee & Sanderman, 1993), and a list of socio-demographic characteristics. The test-booklets that were used at the other nine days, contained the WHOQOL-100 but without the domains IV, V, and VI, the POMS (Wald & Mellenbach, 1990), the Pain Cognition List (PCL; Vlaeyen *et al.*, 1989), and some questions concerning pain and activities.

The RAND-36 is a 36-item generic health status measure. It includes one multi-item scale that assesses eight health concepts: (i) limitations in physical activities because of health problems; (ii) limitations in usual role activities because of physical or emotional problems; (iii) limitations in usual role activities because of physical health problems; (iv) bodily pain; (v) general mental health (psychological distress and well-being); (vi) limitations in usual role activities because of emotional problems; (vii) vitality (energy and fatigue); and (viii) general health perceptions (Ware, 1993). The testing yields a composite QoL score on a scale of zero to 100 (Van der Zee & Sanderman, 1993). The RAND-36 is short and sensitive to intervening illness, for instance, among the relatively healthy elderly. This measure appears to have a good reliability and validity (Bowling, 1995) and it is becoming the most preferred generic instrument in disease-specific batteries.

The POMS was used because it measures five different mood states: Depression (8 items), Neuroticism (6 items), Irritation (7 items), Fatigue (6 items), and Vigor (5 items). The first three scales were used to validate the facet Negative Feelings of the WHOQOL-100, whereas the latter two were used to validate the facet Energy and Fatigue. The regular instruction for respondents is to reflect how one feels the last few days including today. This instruction was changed to refer only to 'this day'. The reliability of the five scales ranges from 0.72 for Vigor to 0.94 for Neuroticism.

The questionnaire that was used to measure some cognitions concerning pain was the PCL. This measure consists of 17 statements with which a respondent can agree or disagree by means of a 5-point Likert type scale. Examples of items are "I feel handicapped by the pain" and "I think that I have learned to live with the pain". The internal consistency of the PCL in the present study was good ($\alpha=0.89$).

Besides the questionnaires described above, a number of separate questions were asked all ten days. These questions were "How often do you have pain?" (*Never-Seldom-Ones in a while-regu-*

larly-Constantly), "At which moment(s) of the day do you have this pain mainly?" (*At night-In the morning-In the afternoon-In the evening*), "What do you do when you are bothered by pain?" (open-ended question), "Taken all things together, how did you feel today?" (7-point scale from *Very bad* to *Very good*), "What activities have you done today?" (open-ended question). In addition, respondents could indicate the extent of their pain that day on a 100 mm visual analogue scale (VAS; Huskisson, 1983), and "How is your health?" (from *Very bad* to *Very good*). Furthermore, there was an opportunity for remarks and space for indicating the time at which they finished completing the test-booklet. They could also indicate how long they worked on the test-booklet.

Finally, respondents were asked to indicate their sex, age, highest education level that they completed, and marital status at day 1.

6.6.2 Results

Reliability

In order to establish the test-retest reliability of the WHOQOL-100, the method as described by Epstein (1979) was used, that is, scores on the facets and domains at times 1, 3, 5, 7, and 9 were averaged for each respondent and subsequently correlated with the scores at times 2, 4, 6, 8, and 10, which had also been averaged for each respondent.

As shown in Table 30, the test-retest reliability of the instrument was extremely good, with correlations ranging from 0.94 for the WHOQOL-100 facet Negative Feelings to 0.99 for the WHOQOL-100 facets Self-Esteem and Social Support.

Construct validity

In order to investigate the construct validity of the WHOQOL-100, the correlations between this instrument and the RAND-36 were calculated at time 1. In addition, correlations between the WHOQOL-100, on the one hand, and the POMS, PCL, EPCL, and the additional questions about pain and activities, on the other hand, were calculated for times 2 to 10.

Although the respondents ($N=12$) only completed the RAND-36 and the entire WHOQOL-100 at time 1, the correlations between the two measures are presented in Table 31 in order to get an idea about the relationship between them. It appeared that RAND-36-General Health Experience correlated highest with the WHOQOL-100 domain Physical Health (Domain I; $r=0.57$) and the facets Pain and Discomfort (Facet 1; $r=-0.48$), Energy and Fatigue (Facet 2; $r=0.55$), and Physical Safety and Security (Facet 16; $r=0.68$). Concerning RAND-36-Emotional Problems, the highest relations were found with WHOQOL-100-Psychological Health (Domain II; $r=0.58$) and

WHOQOL-100-Environment (Domain V; $r=0.68$) at domain level and Body Image and Appearance (Facet 7; $r=0.72$), Home Environment (Facet 17; $r=0.70$), and Physical Environment (pollution/noise/traffic/climate) (Facet 22; $r=0.66$) at facet level.

Table 30. Average test-retest reliability of the WHOQOL-100 with a 24-hours interval

Domains and Facets of the WHOQOL-100	Average correlation between Times 1 to 10
Overall Quality of Life and General Health	0.98
Domain I: Physical Health	0.98
Pain and Discomfort	0.97
Energy and Fatigue	0.96
Sleep and Rest	0.98
Domain II: Psychological Health	0.97
Positive Feelings	0.96
Thinking, Learning, Memory, and Concentration	0.97
Self-Esteem	0.99
Body Image and Appearance	0.96
Negative Feelings	0.94
Domain III: Level of Independence	0.97
Mobility	0.97
Activities of Daily Living	0.95
Dependence on Medication or Treatments	0.98
Working Capacity	0.95
Domain IV: Social Relationships	0.98
Personal Relationships	0.96
Social Support	0.99
Sexual Activity	0.95

With respect to RAND-36-Physical Functioning, significant correlations emerged with the WHOQOL-100 Domain III (Level of Independence; $r=0.67$) and its facets Activities of Daily Living (Facet 10; $r=0.68$) and Dependence on Medication or Treatments (Facet 11; $r=-0.65$). RAND-36-Physical Problem was related to two WHOQOL-100 domains, namely Psychological Health (Domain II) and Environment (Domain V), and three WHOQOL-100 facets: Positive Feelings (Facet 4), Negative Feelings (Facet 8), and Participation in and Opportunities for Recreation/Leisure (Facet 21).

RAND-36-Health Change appeared to be significantly correlated with the WHOQOL-100 facets Activities of Daily Living (Facet 10), Dependence on Medication or Treatments (Facet 11), and Working Capacity (Facet 12) and the domain that these three facets belong to, Level of Independence.

dence (Domain III). The Mental Health scale of the RAND-36 was associated at the WHOQOL-100 facet level with the global facet Overall Quality of Life and General Health (Facet 0), Body Image and Appearance (Facet 7), Negative Feelings (Facet 8), Home Environment (Facet 17), and Participation in and Opportunities for Recreation/Leisure (Facet 21). In addition, at WHOQOL-100 domain level, Psychological Health (Domain II) and Environment (Domain V) were significantly correlated with RAND-36-Mental Health.

Table 31. Correlations between the WHOQOL-100 and the RAND-36-scales

WHOQOL-100	RAND-36-scales								
	GHE	EP	PhF	PhP	HC	MH	Pain	SF	Vi
Facet 0	0.27	0.33	-0.42	0.56	0.02	0.61*	0.35	0.56	0.78**
Domain I	0.57	0.22	0.31	0.32	0.49	0.32	0.60*	0.47	0.39
Facet 1	-0.48	-0.32	-0.26	-0.20	-0.55	-0.26	-0.58*	-0.42	-0.22
Facet 2	0.55	0.30	0.09	0.44	0.36	0.51	0.60*	0.68*	0.64*
Facet 3	0.36	-0.10	0.43	0.14	0.28	0.01	0.29	0.03	0.09
Domain II	0.31	0.58*	-0.28	0.65*	0.12	0.71**	0.61*	0.74**	0.79**
Facet 4	0.08	0.36	-0.42	0.58*	-0.05	0.57	0.40	0.47	0.64*
Facet 5	0.13	0.34	-0.39	0.17	0.26	0.32	0.31	0.51	0.37
Facet 6	0.29	0.22	-0.17	0.53	0.18	0.45	0.41	0.47	0.75**
Facet 7	0.22	0.72**	-0.10	0.49	0.12	0.58*	0.51	0.55	0.54
Facet 8	-0.43	-0.54	0.11	-0.67*	-0.07	-0.75**	-0.65*	-0.82**	-0.78**
Domain III	0.36	0.05	0.67*	0.12	0.72**	-0.05	0.54	0.19	0.12
Facet 9	0.44	0.25	0.50	0.12	0.46	0.13	0.43	0.18	0.14
Facet 10	0.10	0.11	0.68*	0.29	0.70*	-0.07	0.69*	0.25	0.07
Facet 11	-0.34	-0.13	-0.65*	-0.02	-0.75**	0.09	-0.46	-0.12	-0.00
Facet 12	0.37	-0.27	0.53	0.01	0.62*	-0.14	0.33	0.13	0.21
Domain IV	0.22	0.14	-0.49	0.32	-0.27	0.49	0.06	0.24	0.53
Facet 13	0.04	0.02	-0.01	0.08	0.02	0.08	0.06	0.01	0.08
Facet 14	0.15	-0.03	-0.30	0.19	-0.31	0.30	-0.03	0.02	0.34
Facet 15	-0.03	0.17	-0.58	0.25	-0.17	0.41	0.05	0.29	0.49
Domain V	0.44	0.68*	-0.06	0.59*	0.03	0.75**	0.61*	0.65*	0.71**
Facet 16	0.68*	0.46	-0.12	0.10	-0.06	0.57	0.24	0.28	0.45
Facet 17	0.32	0.70*	-0.36	0.54	-0.31	0.80**	0.41	0.54	0.66*
Facet 18	-0.03	0.47	0.04	0.49	0.00	0.42	0.41	0.47	0.45
Facet 19	0.37	-0.08	-0.18	0.30	-0.31	0.36	0.06	0.22	0.41
Facet 20	0.22	0.45	0.26	0.49	0.21	0.39	0.65*	0.47	0.28
Facet 21	0.25	0.53	-0.01	0.68*	0.08	0.66*	0.71**	0.73**	0.73**
Facet 22	0.37	0.66*	-0.24	0.19	0.00	0.54	0.26	0.43	0.40
Facet 23	0.23	0.50	-0.02	0.29	0.20	0.39	0.37	0.29	0.41
Domain VI	0.26	0.23	-0.08	0.34	0.26	0.35	0.44	0.63*	0.57

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; GHE=General Health Experience; EP=Emotional Problem; PhF=Physical Functioning, PhP=Physical Problem; HC=Health Change; MH=Mental Health; SF=Social Functioning; Vi=Vitality

The Pain scale of the RAND-36 appeared to be significantly correlated with the WHOQOL-100 facets Pain and Discomfort (Facet 1), Energy and Fatigue (Facet 2), Negative Feelings (Facet 8), Activities of Daily Living (Facet 10), Opportunities for Acquiring New Information and Skills

(Facet 20), and Participation in and Opportunities for Recreation/Leisure (Facet 21). Furthermore, RAND-36-Pain was significantly related to the WHOQOL-100 domains Physical Health (Domain I), Psychological Health (Domain II), and Environment (Domain V). These correlations were in the expected direction, because the higher one's score on the Pain scale of the RAND-36, the less pain one had reported.

Concerning RAND-36-Social Functioning, significant correlations were found with the WHOQOL-100 facets Energy and Fatigue (Facet 2), Negative Feelings (Facet 8), and Participation in and Opportunities for Recreation/Leisure (Facet 21) and the WHOQOL-100 domains Psychological Health (Domain II) and Environment (Domain V).

Finally, with respect to the RAND-36 scale Vitality, a number of significant relations emerged. At WHOQOL-100 facet level these associations were found with the global facet Overall Quality of Life and General Health (Facet 0), Energy and Fatigue (Facet 2), Positive Feelings (Facet 4), Self-Esteem (Facet 6), Negative Feelings (Facet 8), Home Environment (Facet 17), and Participation in and Opportunities for Recreation/Leisure (Facet 21). At WHOQOL-100 domain level, it appeared that Psychological Health (Domain II) and Environment (Domain V) were significantly related to RAND-36-Vitality (see Table 31).

Table 32. Correlations between the WHOQOL-100 and the POMS

WHOQOL-100	POMS					PCL
	Depr.	Fatigue	Irrit.	Neur.	Vigor	
Overall Quality of Life & General Health	-0.28**	-0.27**	-0.22*	-0.19	0.55***	0.66***
Physical Health	-0.31**	-0.42***	-0.18	-0.26**	0.59***	0.39***
Pain and Discomfort	0.32**	0.44***	0.28**	0.44***	-0.44***	-0.32**
Energy and Fatigue	-0.28**	-0.56***	-0.15	-0.14	0.66***	0.61***
Sleep and Rest	-0.08	0.09	0.02	0.00	0.17	-0.08
Psychological Health	-0.41***	0.04	-0.27**	-0.33**	0.64***	0.77***
Positive Feelings	-0.34***	-0.09	-0.25*	-0.28**	0.57***	0.52***
Thinking, Learning, Memory, & Concentration	-0.22*	0.31**	-0.12	-0.51***	0.23*	0.47***
Self-esteem	-0.29**	0.22*	-0.12	-0.22*	0.46***	0.62***
Body Image and Appearance	-0.23*	0.01	-0.12	0.05	0.55***	0.68***
Negative Feelings	0.49***	0.20*	0.41***	0.35***	-0.63***	-0.67***
Level of Independence	-0.27**	-0.32**	-0.20*	-0.20*	0.50***	0.33**
Mobility	-0.13	-0.34***	-0.12	-0.08	0.37***	0.27**
Activities of Daily Living	-0.29**	-0.33**	-0.20*	-0.19	0.62***	0.47***
Dependence on Medication or Treatments	0.14	-0.00	0.13	0.26**	-0.01	0.31**
Working Capacity	-0.27**	-0.37***	-0.15	-0.05	0.62***	0.56***
Social Relationships	-0.28**	-0.29**	-0.26**	-0.07	0.54***	0.50***
Personal Relationships	-0.17	-0.30**	-0.09	0.28**	0.54***	0.38***
Social Support	-0.09	-0.33**	-0.06	0.26**	0.50***	0.33***
Sexual Activity	-0.29**	0.20*	-0.35**	-0.25*	-0.11	0.13

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; Depr. = Depression; Irrit. = Irritation; Neur. = Neuroticism

In Table 32 the correlations between the POMS scales (scores on times 2 to 10) and the WHOQOL-100 are presented. The results show that POMS-Depression had the highest relationship with the WHOQOL-100 facet Negative Feelings ($r=0.49$). The same outcome was found for POMS-Irritation which correlated 0.41 with the WHOQOL-100 facet Negative Feelings. In addition, both POMS-Vigor and POMS-Fatigue were related strongest with WHOQOL-100-Energy and Fatigue ($r=0.66$ and $r=-0.56$, respectively). The last POMS scale, Neuroticism, was associated -0.51 with the WHOQOL-100 facet Thinking, Learning, Memory, and Concentration. Looking at the WHOQOL-100 domain level, it appeared that Psychological Health had the strongest correlation with POMS-Neuroticism ($r=-0.33$).

Table 33. Correlations between the WHOQOL-100 and five questions concerning pain, health, and activities

WHOQOL-100	Exp	Freq.	Health	Day	Activ.
Overall Quality of Life & General Health	-0.05	0.15	0.52***	0.47***	-0.12
Physical Health	-0.38***	-0.48***	0.65***	0.53***	-0.24*
Pain and Discomfort	0.54***	0.63***	-0.63***	-0.54***	0.10
Energy and Fatigue	-0.10	-0.05	0.63***	0.46***	-0.25*
Sleep and Rest	-0.20	-0.36***	0.15	0.15	-0.16
Psychological Health	-0.25*	-0.02	0.50***	0.51***	-0.23*
Positive Feelings	-0.17	0.13	0.42***	0.42***	-0.18
Thinking, Learning, Memory, and Concentration	-0.34**	-0.14	0.32**	0.25**	-0.08
Self-esteem	-0.23*	-0.11	0.31**	0.44***	-0.21*
Body Image and Appearance	-0.09	0.06	0.32**	0.34***	-0.18
Negative Feelings	0.14	0.05	-0.54***	-0.54***	0.19
Level of Independence	-0.37***	-0.56***	-0.47***	0.58***	-0.18
Mobility	-0.18	-0.41***	0.40***	0.36***	-0.06
Activities of Daily Living	-0.22*	-0.31**	0.44***	0.58***	-0.22*
Dependence on Medication or Treatments	0.40***	0.62***	-0.17	-0.25*	0.05
Working Capacity	-0.19	-0.29**	0.47***	0.63***	-0.24*
Social Relationships	-0.06	-0.32**	0.43***	0.30**	-0.05
Personal Relationships	-0.02	0.24*	0.35***	0.09	-0.13
Social Support	0.13	0.29**	0.30**	0.19	-0.09
Sexual Activity	0.01	0.02	-0.03	0.32**	0.23*

Note: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; Exp=Extent of Pain; Freq.=Frequency of Pain; Activ.=number of Activities

As shown in Table 32, PCL was significantly correlated with all the WHOQOL-100 domains and facets measured except Sleep and Rest ($r=-0.08$) and Sexual Activity ($r=0.13$). When looking at the magnitude of the correlation, it appeared that the highest correlations were found with the WHOQOL-100 domain Psychological Health ($r=0.77$) and its facets Body Image and Appearance ($r=0.68$) and Negative Feelings ($r=-0.67$).

Looking at Table 33, in which the correlations are presented that were calculated across times 2

to 10, it appeared that both Extent of Pain and Frequency of Pain correlated highest with the WHOQOL-100 facet Pain and Discomfort ($r=0.54$ and $r=0.63$, respectively). In addition, although the correlation between the questions concerning their Health and the WHOQOL-100 facet Overall Quality of Life and General Health was 0.52, Health was more associated with the WHOQOL-100 facets Pain and Discomfort ($r=-0.63$) and Energy and Fatigue ($r=0.63$). The respondents' evaluation of the Day correlated 0.47 with the WHOQOL-100 facet Overall Quality of Life and General Health. Again, higher correlations were found with the facets Activities of Daily Living ($r=0.58$) and Working Capacity ($r=0.63$). Finally, the number of Activities were related -0.25 with the WHOQOL-100 facet Energy and Fatigue and -0.24 with the facet Working Capacity.

Norms

In accordance with the other five studies, mean scores and standard deviations of the present RA group are presented here in order to give a first indication of scores that RA patients will receive on the WHOQOL-100. The scores were averaged across times 2 to 10 to get a more robust indication (see Table 34).

Table 34. Average scores and standard deviations of the RA respondents

WHOQOL-100	Mean score	SD
Overall Quality of Life & General Health	13.9	2.4
Physical Health	12.9	2.2
Pain and Discomfort	11.8	2.8
Energy and Fatigue	12.5	3.0
Sleep and Rest	14.1	3.2
Psychological Health	14.7	1.9
Positive Feelings	14.0	2.5
Thinking, Learning, Memory, and Concentration	14.6	2.4
Self-esteem	14.0	2.1
Body Image and Appearance	16.4	2.7
Negative Feelings	9.8	2.9
Level of Independence	13.1	2.0
Mobility	13.5	2.3
Activities of Daily Living	13.5	2.7
Dependence on Medication or Treatments	11.6	3.4
Working Capacity	13.1	2.4
Social Relationships	14.7	2.1
Personal Relationships	15.5	2.4
Social Support	15.5	2.1
Sexual Activity	12.6	2.7

6.7 Conclusion

In general, it appears that the WHOQOL-100 has a good reliability and validity. Concerning reliability, the internal consistency and test-retest reliability were reviewed. The internal consistency of the WHOQOL-100 appears to be very acceptable. The lowest alpha across all six studies was 0.43 for the WHOQOL-100 facet Physical Environment (pollution/noise/traffic/climate) and the highest one was 0.96 for the facet Activities of Daily Living. With respect to the test-retest reliability, it appeared that WHOQOL-100 scores remained fairly stable ($r > 0.70$) for all facets and domains, with the exception of the facets Pain and Discomfort, Self-Esteem, three facets of the Level of Independence domain, Social Support, Physical Safety and Security, Opportunities for Acquiring New Information and Skills, and Physical Environment (pollution/noise/traffic/climate), during a four week interval. Looking at a 24-hours interval, the WHOQOL-100 facets and domains all remained very stable ($r < 0.90$). In this last case it must be added that the domains Environment and Spirituality/Religion/Personal Beliefs were not included.

Concerning the validity of the questionnaire, a number of different aspects were studied. These aspects are content, construct (divergent and convergent), discriminant, and criterion validity. The content validity of the WHOQOL-100, scrutinized in Study 2, seemed very good. In general, the item-rest correlations showed that facets correlated highest with their own domain. The exception to this were all three facets of Domain I, Facet 4 (Positive Feelings), and Facet 16 (Physical Safety and Security).

With respect to the construct (divergent and convergent) validity, it emerged that the questionnaire as a whole as well as with respect to a number of specific facets was good. In general, the WHOQOL-100 correlated moderately with the SIP categories in the expected direction in both Study 1 and 4. Both questionnaires tap into the same construct, but measure different aspects. This makes sense because the SIP is a health status measure, whereas the WHOQOL-100 measures subjective QoL. Furthermore, it emerged that the convergent validity was good, with high correlations between the WHOQOL-100 and the SIP where they were expected to be high, for instance, WHOQOL-100-Thinking, Learning, Memory, and Concentration with SIP-Alertness Behavior, with the exception of the WHOQOL-100 domain Physical Health which was not related to the SIP-Physical dimension. In addition, it became clear from the studies 1, 5, and 6 that a number of WHOQOL-100 facets such as Self-Esteem, Body Image and Appearance, and Negative Feelings are very solid and useful scales compared to other scales measuring the same aspects of QoL. Concerning the divergent validity, it appeared that, in general, the SIP-categories were not related to those WHOQOL-100 facets with which they were not expected to be related.

From Study 2, it emerged that the PGWB was correlated highest with the WHOQOL-100. Furthermore, the GHQ-30 and the LSIA were also related to the WHOQOL-100. In general, for

all three measures (PGWB, LSIA, GHQ-30) the correlations with Domain V were not as high as with the other domains. Again, as in Study 1, it became apparent that the PGWB, the LSIA, the GHQ-30, and the WHOQOL-100 measure the same concept.

As could have been expected, it appeared that LS correlated highest with the WHOQOL-100 facets Personal Relationships and Social Support and lower with the other facets of the WHOQOL-100. Concerning Emotional Well-Being, Neighboring, and Residential Satisfaction, the highest correlations were generally with the expected WHOQOL-100 domains and facets.

In Study 4, the divergent and convergent validity of the WHOQOL-100 are assessed using the SIP, MPVC, BDI, and PANAS. Concerning the disease-specific MPVC, it emerged that its two subscales Well-Being and Feeling of Being Disabled were related to all WHOQOL-100 facets and domains except the facets Overall Quality of Life and General Health, Pain and Discomfort, and Energy and Fatigue and the domain Physical Health. The two MPVC subscales Displeasure and Social Inhibition were especially related to the WHOQOL-100 domain Psychological Health and its facets. The relation between WHOQOL-100 Psychological Health and MPVC-Social Inhibition is not surprising because this last scale mostly consists of questions about social skills and a person's role in groups. The BDI and NA of the PANAS are strongly related to the WHOQOL-100 domains Psychological Health and Level of Independence and their facets, whereas PA of the PANAS only has a high correlation with WHOQOL-100 Psychological Health and its facets Positive Feelings, Thinking, Learning, Memory, and Concentration, and Self-Esteem.

The disease-specific PDI is related to the WHOQOL-100 facets Overall Quality of Life and General Health, Pain and Discomfort, Body Image and Appearance, Negative Feelings, Dependence on Medication or Treatments, and Personal Relationships. At domain level, the WHOQOL-100 Physical Health, Psychological Health, and Social Relationships were related to the PDI.

Study 6 only gives a very preliminary picture concerning the relationship between the WHOQOL-100 and the RAND-36, because only 12 RA patients completed the two instruments only once. However, from these figures it emerged that the correlations were, in general, modest. A larger study should be conducted using these two measures in order to get a better insight in the relationship between these measures.

The WHOQOL-100 appears to be able to make an excellent distinction between healthy persons and CFS patients. Not one single case was misclassified. However, whether this result can be expanded to other samples of ill persons such as rheumatic arthritis patients still remains to be examined.

In accordance with the expectation, it emerged that the WHOQOL-100 correlated reasonably high with two personality scales: Emotional Stability and Extraversion. This seems to indicate that

the WHOQOL-100 is also tapping into these two personality characteristics with persons that are extraverts and emotional stable scoring higher on subjective QoL.

In study 5, an index for the severity of psoriasis, the PASI, was assessed by a dermatologist. When this measure was related to the WHOQOL-100, a relationship emerged between the PASI and two WHOQOL-100 facets: Bodily Image and Appearance and Dependence on Medication or Treatments. Thus, the more severe a person's psoriasis, the lower that person's bodily image and the more dependent that person is on medication or treatment. However, a person's feelings and overall evaluation of his/her QoL and health are not related to the severity of psoriasis.

It might be concluded that the six studies that were presented in this chapter have shown that the WHOQOL-100 is a promising instrument to measure subjective QoL.

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Chapter 7 Conclusion and future development

In 1991, the World Health Organization (WHO) started a project entitled *The assessment of QoL in health care* with the goal to develop cross-culturally a QoL instrument that measures QoL in a very broad sense. In this project, the subjective perspective is the focus of attention. This WHO instrument encompassed an extensive assessment of general subjective QoL which has led to the construction of a QoL scale that consists of global QoL items.

The instrument, called the *World Health Organization Quality Of Life assessment instrument* (WHOQOL-100), is a generic QoL instrument that is applicable to chronically ill persons, individuals living under stress and healthy persons. It has been developed cross-culturally in 15 centres all over the world, namely in Australia, Croatia, England, France, (North and South) India, Israel, Japan, The Netherlands, Panama, Russia, Spain, Thailand, USA, and Zimbabwe.

The construction process of the instrument consisted of a number of steps. First, an expert panel on QoL consisting of representatives of the field centres developed a working definition of QoL and a list of facets (and its definitions) belonging to QoL. In this phase of the project, QoL was conceptualized as "a person's perception of his/her position in life within the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards, and concerns. It is a broad-ranging concept incorporating, in a complex way, the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment" (WHOQOL group, 1994a, p. 28). Subsequently, discussion groups were held in each field centre. The members of these groups were asked to discuss the meaning of the term *quality of life* and what facets they thought belonged to it. After adapting the initial list of QoL facets incorporating the remarks of the members of the discussion groups, at least six focus groups were run in each field centre consisting of lay persons, persons suffering from a chronic illness, and health professionals. The members of these focus groups were asked whether they missed particular facets in the list or whether some facets did not belong to the list. In addition, the definitions of the various facets were discussed. Finally, the participants were asked to suggest items for probing into the facets. Thus, the WHOQOL-100 is developed from the perspective of laypersons, that is, healthy as well as chronically ill individuals. On the basis of the transcripts of the focus groups and the criteria set for writing **items**, the pilot version of the instrument was developed and then tested (WHOQOL group 1994a, 1995a).

The WHOQOL pilot instrument was administered to at least 250 ill and 50 healthy persons in each of the 15 field centres. The analysis plan aimed at examining the content validity of the

WHOQOL domains and facets, selecting the best questions for each facet, and establishing the WHOQOL's internal consistency and discriminatory capacity (WHOQOL group, 1995a). Based on the analyses, the so-called WHOQOL-100 or WHOQOL Field Trial Form (WHOQOL group 1995b; Dutch version by De Vries & Van Heck, 1995) was developed.

From the studies with the Dutch WHOQOL-100 presented in chapter 6, this measure appears to have a good reliability and validity. At this moment, the psychometric properties of the WHOQOL-100 are still being tested in all centres. In addition, further developments are underway such as several short forms and modules. Furthermore, new centres like Germany, Sweden, and China are joining the WHOQOL project. These developments are discussed below.

7.1 Short forms

At this moment, WHO is working on short forms of the WHOQOL-100. In order to create these short forms, all centres are now collecting new data. The data gathered in the Dutch centre, as discussed in chapter 6, has been sent already to WHO. During the meeting of the WHOQOL group in Montreal in 1995, two approaches for item reduction were discussed: an empirical and an theoretical approach. In the latter, the construct of *quality of life* is taken as the starting point on the basis of which the researchers themselves decide which facets and items will constitute the shorter version. In the empirical approach, the psychometric characteristics of the facets and items will be used to develop the shorter version. It was decided that both approaches will be used to reduce the size of the WHOQOL-100 (WHOQOL group, 1995c).

Different short forms will be developed for different purposes. For instance, a 25-item version will be made consisting of one item for each facet. In this way an indication of respondents' QoL can be given based on the inclusion of the entire range of facets. The completion of this version would only take about 5 minutes. However, the interpretation of the results can only be discussed at the domain level, because one item scales tend to be not very reliable (e.g., Greaner & Penner, 1982).

An alternative short form will contain only the domains Physical Health, Psychological Health, and Level of Independence. Two items from each facet belonging to these domains will be retained. This short form can be used in, for instance, clinical trials, where the interest is not in the total QoL of the respondents, but the focus is on changes in these particular domains. With this short form, the results can be used both on facet level and domain level.

In another short form, only the domain Environment is not included. In addition, this version contains more items from the first three domains than for Social Relationships and Spirituality/Religion/Personal Beliefs. Persons who are not interested in the environmental aspects can use this

version.

At the meeting mentioned above, it was decided that a shorter version may be used with modules, for instance, with cancer patients.

7.2 Modules

The WHOQOL-100 is a so-called *core* instrument. The instrument developed so far is the so-called core instrument, the WHOQOL-100. This means that it assesses a broad entity which is important to practically every individual. However, there are certain groups of persons whose QoL might not be sufficiently or appropriately assessed with the WHOQOL-100. For instance, asking terminally ill persons about their positive feelings with respect to the future is highly inappropriate and might raise irritation. In such instances, it would be necessary to develop a module for the instrument that can address the unique circumstances of such individuals or groups. A module is defined as a special set of facets, sub-facets, and/or questions that complement the core instrument for a particular group. In addition, wherever necessary, the questions within the core may also need to be revised for a module, as in the example given above. Modules will always have to be used in combination with the core instrument. Therefore, a module is called an *add-on module*.

Right from the start of the WHOQOL project, the following five priority areas for module development were identified: (i) persons suffering from chronic disease (e.g., epilepsy, arthritis, cancer, diabetes); (ii) caregivers of the ill or disabled (e.g., a person taking care of a demented or terminally ill patient); (iii) persons living in highly stressful situations (e.g., elderly people living in poorly run institutions, refugees in camps); (iv) people with difficulty in communicating (e.g., persons with severe learning disabilities, blind persons); and (v) children (WHO, 1991).

For those groups with difficulty in communicating about the quality of their lives (e.g., young children, Alzheimer's patients, mentally retarded individuals, individuals with a learning disability), it would be particularly important to maintain the patient-orientated basis of the instrument (WHO, 1993). This is important in view of the consistent reports that there has been observed only low associations between patients' and practitioners' ratings of QoL (Hamera & Shontz, 1978; Pearlman & Uhlmann, 1988; Slevin, Plant, Lurch, Drinkwater, & Gregory, 1988; Sprangers & Aaronson, 1992). In addition, there are the problems that are associated with proxy forms of instruments (Rothman *et al.*, 1991).

Modules, also within the priority areas, will only be developed when a number of criteria are met. These criteria for the development of a module for the WHOQOL-100 are: (i) the module will be of utility to practitioners, researchers, and/or policy makers; (ii) the core instrument alone does not appropriately or sufficiently assess the QoL of the target group; (iii) there are no existing instruments with adequate psychometric properties of validity, reliability, and responsiveness to

change, and; (iv) approval for the development of a given module has been obtained from the WHOQOL group, WHO, Geneva. Because the philosophy of the WHOQOL-project is that the WHOQOL-100 - the core instrument - measures all aspects of QoL that are relevant to every individual, the number of modules that will be developed will be kept to a minimum.

Currently, a number of WHOQOL centres are working on the development of add-on modules for cancer and schizophrenia. Another group of persons for whom the WHOQOL-100 is probably not fully adequate are refugees. A literature review on QoL in refugees done in 1994 (De Vries and Van Heck, 1994a, 1994b) and an explorative study with Tamil refugees living in camps in Southern India (De Vries, Van Heck, Rajkumar, & Nakkeerar, 1994, 1995) will be taken as the starting point for the development of the QoL instrument for refugees living in refugee camps, the WHOQOL-REF.

It is certain that in the future the necessity for other modules will be explored. Topics that will probably have to be reviewed concerning the usefulness of the WHOQOL-100 are the QoL in children and elderly.

7.3 New centres

Now that the WHOQOL-100 exists and the reliability and validity of the instrument is being tested, new centres who are interested in developing their own regional or language version of the instrument can contact the WHOQOL coordinating centre. A prospective centre will have to consider a number of issues; namely (i) the usefulness of the instrument in that centre, (ii) the compatibility of the purposes of the WHOQOL with the requirement of the culture, (iii) the availability of existing QoL measures with a good reliability, validity, and responsiveness to change, (iv) the compatibility of the WHOQOL approach with the new investigator/centre, (v) the accessibility of funding for the WHOQOL work, and (vi) the feasibility of the work outlined in the protocol (WHOQOL group, 1994c). When the prospective centre thinks that these issues apply, then, they will have to ask the coordinating centre of the WHOQOL group for permission to join the project.

The procedure that new centres who join the WHOQOL project will have to follow, is outlined in the protocol for new centres (WHOQOL group, 1995b). In general, the procedure consists of the same steps as the initial development of the WHOQOL-100. First, the WHOQOL-100, including instructions, headers, the demographic data sheet, and the facet definitions, will have to be translated into the national/regional language of the new centre according to the translation method outlined in Appendix III. Using these documents, at least four *focus* groups will have to be conducted; two with health care personnel and two with patients, in order to discuss whether or not

national items will be needed and if so, give suggestions. A question writing panel will generate any national items for the existing facets on the basis of the focus group transcripts. Subsequently, response scales should be developed using the methodology described in paragraph 5.1.2. Third, the instrument should be pre-tested in order to get preliminary feedback. This step is followed by the administration of the pilot WHOQOL among at least 50 healthy persons and 250 persons with a disease or impairment. In the final step, the psychometric properties of the new version of the WHOQOL will have to be established.

At this moment some new centres have already joined the WHOQOL project. For instance, one of the new centres is located in La Plata (Argentina). Because people in Argentina speak Spanish, they will take the Barcelona version as a starting point. In such a case, in which the people in a new centre speak the same language as an older, already established centre, the translation part can be left out.

Other new centres that have already started their WHOQOL work are China, Hong Kong, Germany (Mannheim), Italy (Bologna), Norway (Bergen), Sweden (Mölnadal), and Pakistan (Rawalpindi). Since there does not exist a WHOQOL version in the local language, these centres will have to start with the translation step. The Hong Kong centre will develop a Cantonese Chinese version in collaboration with the Chinese centre. In these two centres the translation work is progressing. The German centre has started conducting focus group at the end of 1995. The Italian, Norwegian, and Swedish centres all have started their translation work in the summer of 1995, whereas in Pakistan they have started the translation in september 1995.

Two other sites - Brazil (Porto Alegre) and Canada (Victoria) - are interested in joining the WHOQOL project. It is expected that these sites will become new centres in the very near future.

Future prospects

It is expected that the number of centres in the WHOQOL project around the world will grow in the future. The old centres, that is, the centres that were in the project from the very start, will give advice and assistance to new centres whenever they are asked. The old centres, among which the Dutch centre, will continue scrutinizing the validity and reliability of the WHOQOL-100, working on the development of short forms and testing their psychometric properties, providing information to national persons who are interested in the WHOQOL-100, and making the instrument available to persons in their country.

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APPENDICES

APPENDIX I

Provisional structure of quality of life

Domain I

Bodily states and functions

- a) Bodily states
 - 1. Pain and discomfort
 - 2. Vitality and fatigue
 - 3. Eating/food and water supply
- b) Bodily functions
 - 4. Sexual function
 - 5. Sleep
 - 6. Bodily movement (excluding mobility)
 - 7. Walking and mobility
 - 8. Sensory functions, e.g. hearing and seeing

Domain II

Psychological functions

- a) Cognitive functions
 - 9. Cognitive functioning
- b) Emotional functions
 - 10. Positive affect/happiness
 - 11. Negative affect/emotional distress
 - 12. Hopefulness
- c) Self concept
 - 13. Self efficacy/ Self-esteem/ Ability to plan
 - 14. Body image

Domain III

Levels of independence

- 15. Ability to carry out activities of daily living
- 16. Dependence on substances
- 17. Communication capacity
- 18. Working capacity
- 19. Participation in and opportunity for recreation and pastimes

Domain IV

Social relationships

- 20. Isolation/ Social contact
- 21. Family support
- 22. Support from friends/acquaintances
- 23. Activities as provider/supporter
- 24. Sexual relationships

Domains V

Environment

- 25. Physical safety and security
- 26. Quality of home environment
- 27. Quality of work environment
- 28. Employment status
- 29. Educational opportunity
- 30. Financial status
- 31. "Costs" of obtaining care

Introducing the WHOQOL

The World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being not merely the absence of disease . . ." and aims for "Health for All" by the year 2000. There are few issues more important in health care than the effect that disease and treatment have on the quality of a person's life. To some people quality of life means "a desirable standard of living". In line with the WHO's definition of health, quality of life is seen as including many factors, ranging from physical well being, through mental health, to social relationships, independence and the quality of a person's environment.

Disease and illness can affect an individual's quality of life in a very profound way. The WHO is coordinating a cross-cultural study to develop an instrument that can assess quality of life (the WHOQOL) for use in health care settings. The WHOQOL will provide a way for health care workers to understand and better help patients under their care.

Your help in developing the WHOQOL is invaluable. It would be helpful if you could bear the following points in mind. The areas we outline below are those which much previous work has suggested are important to people's quality of life. We would like you to consider these areas before arriving for the discussion group. The purpose of the discussion group in which you will take part is to gather your views about issues in quality of life as well as to ask you to think about ways you would ask someone about how these issues relate to people's quality of life. When thinking about these issues it is important to bear in mind that the WHOQOL will be used to ask people about their quality of life in the previous two weeks. We will also ask you to complete a few short questionnaires. We hope you will find the discussion group an interesting and enjoyable experience.

Many thanks for all your help.

Facet 1: Pain and discomfort

Questions should explore unpleasant physical sensations experienced by a person and, the extent to which these sensations are distressing and interfere with the person's life. Questions should also explore the ease with which a person can get relief from pain. The easier the relief from pain, the less the effect of pain on quality of life. Similarly changes in levels of pain may be more distressing than pain itself. Even when a person is not actually in pain; either through taking drugs or because the pain is by nature on and off e.g. migraine; their quality of life may be affected by the constant threat of pain.

Unpleasant physical sensations such as stiffness, aches, long-term or short-term pain, or itches should be included. Pain is judged to be present if a person reports it to be so, even if there is no medical reason to account for it.

The questions should exclude an assessment of the quality, intensity, duration or specific characteristics of the pain, or its cause. Nor should the questions be concerned with the intensity of diffuse aches / pains but rather a person's tolerance for it (or lack of tolerance), the distress caused by it and the interference it causes.

Examples:

- A person taking pain relieving drugs may not be in pain, but their quality of life may be affected by the constant threat of pain
- Intermittent severe migraine with possible threat of severe pain as the major feature
- Chronic rheumatoid arthritis

Facet 2: Vitality and fatigue

Questions should explore the energy, enthusiasm and endurance a person has to perform the necessary tasks of daily living, as well as other chosen activities such as recreation. This may extend from reports of disabling tiredness to adequate levels of energy, to feeling really alive. Tiredness may result from any one of a number of causes such as illness, problems with nerves such as depression, or over-exertion.

The questions should include:

- (a) a sense of physical weakness or tiredness in performing daily activities and leisure;
- (b) how rapidly the person fatigues and;
- (c) whether the person avoids doing things because of fatigue.

Questions should exclude any impairment in daily living due to disability (covered in other areas on physical health) or the impact of fatigue on social relationships (covered in Social relationships). In addition, the reason for any fatigue is beyond the scope of questioning.

Questions should focus on the extent to which fatigue affects the general level of activities performed.

Examples:

- Physical conditions: disease: "viral infections" "liver problems"
- Psychological conditions: depression may result in low level of energy and fatigue.
- Parents of young children, people living in poverty or starvation.

Facet 3: Sexual activity

Questions about sexual activity should explore a person's urge and desire for sex. Additional questions should explore the extent to which the person is able to express and enjoy their desire appropriately.

Questions ought not to be too direct or abrupt and yet should cover sexual desire and outlets and its impact on quality of life. Responses to these questions in some cultures may be more guarded. It is expected that people of different ages and men and women will answer these questions somewhat differently. In addition aspects of a sexual relationship to do with support and intimacy should be excluded as this is covered elsewhere (Social relationships).

Questions should exclude the value judgments surrounding sex and should address only the relevance of sexual activity to a person's quality of life.

Questions should focus on sexual desire, the ability to express and enjoy this desire and the need for and fulfillment of sexual intimacy.

Facet 4: Sleep

Questions should explore how much sleep problems affect the person's quality of life. Sleep problems include difficulty getting off to sleep, waking during the night, waking early in the morning and being unable to get back to sleep, and lack of refreshment from sleep.

Questions should exclude specific features of sleep, such as early morning wakening. Questions should disregard whether the person takes sleeping pills. The question of dependence on sleeping pills is covered in a separate area on dependence on substances.

The questions should focus on whether sleep is disturbed or not, and this can be for any reason, both to do with the person or to do with their environment. Another focus of questioning should be on whether sleep refreshes the person sufficiently for them to carry out their daily tasks without discomfort due to disturbances in sleep.

Examples:

- Parents of small infants
- Shift workers

Facet 5: Motor functioning

Questions in this facet should explore the person's view on his/her ability to move, and control their bodily movements.

Questions should exclude mobility in the more general sense of moving around by foot and by other means of transport as this is covered in separate areas (Mobility and Transport). However, it is likely that this more general mobility will be affected by the control and coordination with which the questions asked here are concerned. Questions should not explore specific bodily movements, e.g., how much trouble do you have with lifting your (left) arm or specific bodily impairment, e.g., loss of leg.

Questions on a person's control over their movements should focus on the following aspects:

1. Ability to move the body without any (physical) limitations.
2. Ability to control movements.
3. Ability to coordinate bodily actions, e.g., walking.

Examples:

- Immobile groups
- Accident victims
- Arthritics

Facet 6: Mobility

Questions on mobility should explore the person's view of their ability to move from one place to another, to get around the home, move around the work place, or to and from transportation services.

Questions should exclude the means a person uses, e.g., a wheelchair or cane. It should also exclude the kind of transportation a person uses (e.g., the bus or car) as this is covered in another area (Transport) and does not bear directly on an individual's personal mobility.

Questions should focus on the person's general ability to go wherever they want to go, and move about the house without the help of others regardless of the means they use to do so.

Examples:

- Elderly
- Agoraphobics
- Arthritics
- Accident victims

Facet 7: Sensory Functions

The questions should explore the person's view of whether their hearing and/or eye sight allow them to engage in activities they need or want to do (with hearing aids or glasses if necessary).

Questions should include the ways in which impairments in vision or hearing affect the person's ability to perform tasks of daily living, as well as participate in and enjoy everyday life.

However, questions should exclude the way in which problems with vision and hearing might affect mobility, aspects of concentration and learning, self-efficacy, independence and social relationships as these are covered in separate areas. In addition particular aspects of hearing/vision (e.g., color discrimination) should be excluded.

Questions should focus on how hearing/vision might affect the individual's quality of life.

Examples:

- Elderly
- Blind
- Deaf

Facet 8: Thinking, Learning, Memory, and Concentration

The questions should explore a person's view of his/her thinking, learning, memory, and concentration.

Questions should include:

- (a) the speed of thinking, creativity and clarity of thought;
- (b) sensitivity to other people's reactions to his/her way of thinking or behaving;
- (c) ability to remember in the short-term and long-term and;
- (d) the ability to focus on something without being distracted.

Questions should exclude a person's ability to communicate as this is covered in another area (Communication Capacity). Questions should exclude whether an individual is alert, aware or awake, even though these underlie thinking, memory and concentration.

Examples:

- People living under conditions of extreme stress
- People with anxiety or depression
- People with dementia
- People with brain damage from trauma, stroke or alcohol abuse

Facet 9: Happiness and Contentment

Questions should explore how much a person experiences positive feelings of contentment, balance, peace, happiness, and enjoyment of the good things in life.

Questions should include a person's day to day feeling of emotional well-being, and aim to focus on positive feelings. Negative feelings of depression and anxiety should not be asked about as these are covered elsewhere.

In phrasing questions the meaning of this aspect of emotional well-being within the culture should be taken into account.

Facet 10: Depression

Questions should explore how much a person experiences negative feelings of despondency, sadness, guilt, tearfulness, despair and a lack of pleasure in life.

Questions should exclude feelings of helplessness (Self-Efficacy), poor concentration (Cognitive functions), anxiety, and the relationship between depression and the person's social relationships. Questions should be able to include individuals who have very severe depression or who suffer from mania.

Questions should focus on feelings of distress and unhappiness.

Examples:

- A person with a chronic illness who becomes depressed
- A woman who becomes depressed following the birth of a child

Facet 11: Anxiety

Questions should explore the degree to which the person experiences nervousness and anxiety. This might range from little or no anxiety, to some nervousness including uneasiness and apprehensiveness to more severe forms of anxiety involving fear, trembling, racing heart, light headedness and sweating.

Questions should exclude any detailed assessment of the severity of the anxiety. Nor should the use of substances to control anxiety be addressed, as dependency on substances is addressed elsewhere.

Questions should focus on how stress interferes with quality of life.

Examples:

- A person in the aftermath of trauma such as a rape or a natural disaster

Facet 12: Hopefulness and Optimism

Questions should explore the person's view of their future. This might range from optimism of a purposeful and meaningful kind, to hopelessness and pessimism.

Questions should include the person's plans, hopes and expectations for the future, but should exclude any in depth exploration of these. Questions should also be able to include answers from individuals who feel very uncertain about their future or have perhaps even considered suicide.

Instead the focus should be on how the person perceives and feels about their future.

Examples:

- Refugees
- Individuals with terminal illnesses

Facet 13: Self-Esteem

Questions should explore how the person feels about themselves as a person. This might range from feelings positive about themselves to feeling extremely negative about themselves. An individual's sense of their worth as satisfaction with themselves should be explored.

Questions should include the person's attitudes towards themselves in a range of areas including how they are able to get along with other people, their education, their family relations and more personal issues. Questions should be able to tap into the sense of dignity and self-acceptance that a person feels.

Questions should exclude very specific reference to social relationships and work satisfaction as these are covered in different areas. However, the sense of self-worth that comes from these activities should be covered by questions at a more general level.

The phrasing of questions should bear in mind that some individuals may find self-esteem difficult to talk about.

Facet 14: Self-Efficacy

Questions should explore the respondent's perception of whether they feel that they are able to do what they actually want to do. That is to say, believing themselves capable of fulfilling their own expectations and goals. This involves a person's feeling of confidence in themselves, and overall feelings of success and failure. Questions should include the person's ability to cope with the problems of everyday living.

As with other questions, questions should stress the person's state at the time, rather than something about their personality. Questions therefore should not dwell upon a person's feelings about their past successes and failures so much as their current experience of control over their environment and life. Questions should not cover how a person feels about their appearance which is covered in a different area (Bodily Image).

Questions will refer to tasks that have to be done, and the extent to which the individual feels capable of doing these tasks. Implied in the phrase "have to" is the pressure both from outside the individual (employer, family ...) and from within (ambition, personality type ...).

Facet 15: Body Image

The questions should explore the person's view of their body. That is to say whether they feel positive or negative about the appearance of their body.

Questions should include the extent to which 'perceived' or actual body impairments, if present, can be corrected (e.g. by make-up, clothing, artificial limbs, etc.).

Questions should exclude the person's view about how much body impairments (e.g., overweigh, amputated arm, etc.) interfere with their performance in activities. Questions on whether the person's body image affects his/her social contacts should not be included since this is covered in another area.

Questions should focus on the person's satisfaction with the way they look and the effect it has on their view of themselves.

Questions should be phrased so as to encourage respondents to answer how they really feel rather than how they feel they should respond. In addition questions should be phrased so as to be able to include a whole range from an individual who is happy with the way they look to someone who is severely physically handicapped.

Examples:

- Mildly overweight
- Disfigured groups, e.g. breast cancer, some skin diseases, amputees
- Weight disorders, e.g. obesity, anorexia nervosa
- Physically handicapped

Facet 16: Ability to Carry out Activities of Daily Living

The questions should explore a person's ability to perform usual daily living activities. The questions should include self-care, and caring appropriately for property.

The questions should exclude aspects of daily living which are covered in other areas, namely specific activities affected by fatigue, sleep disturbances, depression, anxiety, mobility and so on. Questions should disregard whether a person has a home or a family.

Questions should focus on a person's ability to carry out activities, which the person is likely to need to perform on a day to day basis.

Examples:

- Homeless
- Refugees
- Mental and other inpatients

Facet 17: Dependence on Substances

The questions should explore a person's dependence on substances for supporting his/her physical and psychological well-being at a desired level. Dependence on substances may in some instances affect a person's quality of life in a negative way (e.g. alcoholism) whilst in other cases dependence on substances may enhance an individual's quality of life (e.g. cancer patients using pain killers).

The questions should include the person's use of substances both for lessening suffering and for pleasure giving motives. An attempt should be made to include any adverse side effects of drugs on a person's quality of life.

The questions should exclude anything about either the type of substances or drug habits of a person.

Questions should focus on a person's attitudes towards his/her practices of using substances, and the way in which they feel their use of substances affects their quality of life.

Examples:

- Adolescents
- Inpatients in special settings
- Prisoners

Facet 18: Communication Capacity

The questions should explore a person's capacity to relate their thoughts, needs and feelings to others, and also their capacity to understand other people's messages. Questions should explore the extent to which these messages are conveyed and understood as they were intended.

Questions should include speaking and non-verbal messages, but also the capacity to read and write (where this is appropriate).

Questions should exclude social isolation (covered under Social Isolation), stigmatization, and other social reasons why a person is unable to communicate as these issues are covered elsewhere.

Assessment will occur regardless of the state of health, age, sex, education, social group or environmental conditions of the respondent.

Phrasing should allow the inclusion of all forms of communication.

Examples:

- Physical or psychological diseases or problems (e.g. aphasia)
- Prisoners or refugees
- Isolated persons

Facet 19: Working Capacity

The questions should explore a person's use of his or her energy for work or other major activities.

Major activities might include paid work, unpaid work, voluntary community work, care of children and household duties. As such questions should include reference to these possible types of major activities.

The questions should exclude how a person feels about the nature of the work that they do, and the quality of their work environment. These are covered elsewhere (see Quality of Work Environment and Employment Status). In addition, questions should disregard the type of work a person does, or whether they are unemployed. Instead, questions should focus on a person's ability to perform work in general and not a particular job.

Examples:

- Someone forced into unemployment by a factory closure can still use his or her energies for work of other kinds
- A person taking care of a child at home or a chronically ill family member should be rated as capable of work

Facet 20: Participation in and Opportunity for Recreation and Pastimes

The questions should explore a person's ability, opportunities and inclination to participate in leisure, pastimes and relaxation.

The questions should be able to include all forms of pastimes, relaxation and recreation. This might range from seeing friends, to sports, to reading, to watching television or spending time with the family, to doing nothing.

Questions should focus on four aspects: the person's desire for, capacity for, opportunities for and enjoyment of recreation and relaxation. Questions should of course focus on how these relate to a person's quality of life.

Examples:

- Physical or psychological disabilities or diseased persons
- Elderly

Facet 21: Isolation/Social Contact

Questions should explore the amount of contact that a person has with other people. This might range from seeing no one at all to contacts that are sufficient both in number and quality. The reasons for the level of social contact/isolation may be due either to the person or their situation.

Telephone contact should be included as social contact and questions therefore should not imply that the contact requires meeting people face to face. The questions used, therefore, should allow this broader implication of "social contact". This facet would include contacts from professional helpers and workers in social agencies, contacts through similar interest groups of one kind or another, contacts with shop-keepers and other service workers.

The facet should exclude contact with family members and friends as this is included in another area (Family Support and Support from Friends/Acquaintances).

Questions should focus more on the frequency and opportunities for social contacts, since the quality and nature of contacts is covered elsewhere. The focus, therefore, is on the person's satisfaction with and perception of the social contacts obtained.

Examples:

- Displaced persons such as refugees
- The immobile
- People who have moved house away from their social network

Facet 22: Family Support

Questions should explore how much the person feels the commitment, concern, practical assistance and approval of their family, including where appropriate their partner. Questions should also explore the extent to which the person feels that their partner and family share in responsibility, and work together to solve family and personal problems.

Questions should include the extent to which the person feels they receive approval and encouragement from their partner and family. In particular, questions should include the extent to which they perceive their family would be able to offer both emotional and practical help at times of crisis. The extent to which the person feels that they can share moments of happiness and success with their family should also be included. A sense of loving and being loved should be included.

Questions should exclude support from non-family members. As with other areas it is the person's perception rather than external reality to which questions should refer.

Questions should focus on how much the person feels that they have a happy family life that meets their various needs.

Family 23: Support from Friends/Acquaintances

The questions should explore the degree to which a person feels the friendship, commitment and support of people outside the family. Questions should explore the extent to which a person could obtain support when ill or without resources, or at other times, could share problems and hoys with friends and acquaintances, and could rely on friends and acquaintances to understand and identify with his or her situation. Questions should also explore the extnet to which a person feels able to express feelings and needs to family members or friends and acquaintances.

Questions should include the impact on social relationships of other areas, such as stigmatization through physical or mental handicap or aspects of the person's environment which might affect their social relationships. Questions should be able to include all sorts of friendships, from friendship between men, colleagues at work

Questions should focus on the extent to which the person feels that their friends and acquaintances provide him/her with the support that meets his/her needs.

Facet 24: Activities as Provider/Supporter

The questions should explore a person's commitment to and current experience of caring for other people. The questions should include the extent to which he/she obtains satisfaction from, or has problems managing the burdens of such responsibilities. These may include financial sacrifices, and reduced chances to undertake paid work or social activities outside the home. The person may feel that other family members share these responsibilities, or that others do not understand, and leave him/her isolated.

The questions should be able to include parents of young children, people who care for a disabled family member, and others who have people economically or emotionally dependent on them.

Questions should exclude the extent to which other aspects of the person's functioning might limit their activities as provider/support (e.g. communication difficulties, Working Capacity).

The questions should focus on the person's view of their caring and providing for others, and in particular how this affects their quality of life.

Examples:

- Mothers of mentally handicapped children may feel abandoned by the community and by other family members in the lifelong task of care
- The son of a frail mother in an institution may visit her weekly or daily and have a sense of guilt and responsibility for her condition

Facet 25: Religion

Questions hould explore the persons religious convictions and ask how these related to their quality of life. Questions should be able to include people with differing established religions (Roman Catholic Church, Buddhism, Islam ...) as well as people with their own personal spiritual beliefs that do not sit within a particular religious label.

Questions should focus on how a person's spiritual beliefs contribute to their feeling of well-being.

Facet 26: Freedom, Physical Safety and Security

The questions should explore the person's sense of freedom and safety and security from physical harm. A threat to freedom, safety or security might arise from any source such as other persons or political oppression. Thus questions should allow answers that range from a person having the opportunities to live without limitations, to the person living in a state or neighborhood that is oppressive and felt to be unsafe.

Questions should include the extent to which the person feels that there are 'resources' which protect or might protect their sense of safety and security. In addition, attention should be paid to not exclude certain groups for whom this areas might have particular meaning, such as victims of disasters, the homeless, individuals, in dangerous professions, relations of criminals, and victims of sexual abuse.

Questions should not explore in depth the feelings of those who might be seriously mentally ill and perceive that this safety is treasented by odd things such as "being persecuted by aliens".

Questions should focus on a person's own feelings of freedom, safety/lack of safety, security/insecurity in so far as these affect their quality of life.

Examples:

- Refugees
- Prisoners
- People living under political persecution

Facet 27: Quality of Home Environment

Questions on the home environment should explore the quality of the physical state of the principal place where a person lives (and at a minimum sleeps and keeps most of his/her possessions). The quality of the home would be assessed on the basis of being comfortable.

Other areas which might be included are: crowdedness; the amount of space available; opportunities for privacy; facilities available, such as electricity, toilet, running water; and the quality of the construction of the building, roof leaking, and dampness.

Questions to which there can only be two possible answers (such as "Are you connected to electricity?"), the answer to which give little information about the quality of life, should be avoided. In addition questions concerning how well the person is able to move around their home (Mobility, Motor Functioning) and questions about social relationships within the home (Social Relationships) should also be excluded as these are covered elsewhere.

The quality of the immediate neighborhood around the home is important for quality of life, and questions should include reference to the immediate neighborhood.

Questions should be phrased to include the normal work for 'home', i.e. where the person normally lives with their family. However, questions should be phrased so as not to include people who do not reside in one place with their family, such as refugees, or people living in institutions. It would not usually be possible to phrase questions to allow homeless people to answer meaningfully. However, if the questions were phrased with "place you live in", 'Place you stay in" then it would be possible to include more groups of people.

Examples:

- Slum dwellers
- People in institutions
- People who choose to live rough on the streets

Facet 28: Quality of Work Environment

The questions should explore the person's view of the comfort and safety of the place or places in which their work is performed.

Questions should include the atmosphere created by the people who work there and the physical comfort of the work place. The work "work" is used loosely to include any major activity in which the person is involved such as full-time voluntary work, bringing up children and homemaking. The social climate includes interactions between colleagues, and the relationships between employer and employee.

The questions should be phrased to allow people to answer whether or not they are in a paid job, or working inside or outside the home.

Examples:

- Factory workers
- Management in a large enterprise
- Outdoor workers employed by a city
- Mothers with small children at home, engaged in child care and household duties.

Facet 29: Work Satisfaction

Questions should explore the person's satisfaction with the work that he or she performs. This is likely to be affected by how well the work fits with his/her training or experience and with his/her preferences.

Questions should include individuals employed by another, self-employed, working full-time, part-time or unemployed. Thus, "work" is taken to mean any major activity in which the person is engaged.

Questions should exclude anything about the person's capacity for work (Working Capacity) or the quality of their work environment as these are covered in separate areas.

Questions should focus on the person's perception of the value of their work, how satisfied they are with their work status (full-time, part-time, housewife etc.) and the relationship this has to their quality of life.

Examples:

- Full-time employee
- Part-time worker who wishes to be fully employed
- Unemployed manager
- Casual laborer who is usually unemployed

Facet 30: Opportunities for Acquiring Information and Skills

Questions should explore a person's opportunity to learn new skills, acquire new knowledge, and feel in touch with what is going on. This might be through formal education programs, or through adult education classes or through recreational activities, either in groups or alone (e.g. reading).

This should include being in touch and having news of what is going on, which for some people is broad (the "work news") and for others is more limited (village gossip). Nevertheless a feeling of being in touch with what is going on around them is important for many people and should be included.

Questions should focus on an individual's chances to fulfill a need for information and knowledge whether this refers to knowledge in an education sense, or to local, national or international news that bears in some way on the individual's quality of life.

Questions should be phrased so as to be able to capture these different aspects of acquiring new information and skills ranging from world news and local gossip to formal educational programs and vocational training.

Facet 31: Financial Status

The questions should explore the person's view of how their financial resources (and other exchangeable resources) meet their needs for a healthy and at least comfortable life style.

The questions should include a sense of satisfaction/dissatisfaction with those things which the person's income enables them to obtain. Questions should also include a sense of the dependence/independence afforded by their financial resources (or exchangeable resources), and the feeling of having enough.

Questions should focus on what the person can afford or not afford which might affect the quality of their life.

Assessment will occur regardless of the respondent's state of health or whether the person is employed or not.

Examples:

- Mentally or physically handicapped or disabled persons
- Acute or chronic illness
- Elderly people
- Refugees
- Homeless groups
- Unemployed persons

Facet 32: Availability to and Quality of Health and Social Care

Questions should explore the person's view of the health and social care in the near vicinity. "Near" is the time it takes to get help.

Questions should include how the person perceives the availability of service as well as the quality and completeness of care that they receive or expect to receive should they require the services of the health care system. Questions should include voluntary community support (religious charities, temples ...) which either supplements or may be the only available health care system in the respondent's environment. Questions should include how easy/difficult it is to reach local health and social services and to bring friends and relatives to these facilities.

The focus is on the person's view of the health and social services. In addition questions should not ask about aspects of health care which has little personal meaning or relevance to the person who will be answering the question.

Questions should focus on:

- (a) how accessible the person believes the service to be;
- (b) the overall cost of health and social care to the person and;
- (c) the perceived quality of the health and social care which the person receives and/or anticipates receiving

Facet 33: Transport

Questions on transport should explore the person's view of how available or easy it is to find and use transport services to get about.

Questions should include any transport that might be available to the individual (bicycle, car, bus ...).

Questions should exclude anything about the type of transport, nor should they explore means that are used to get about in the home itself. In addition the personal mobility of the individual should be excluded as this is covered elsewhere (Mobility).

Questions should focus on how the available transport allows the person to perform the necessary tasks for daily living as well as the freedom to perform tasks which they choose.

Examples:

- Persons living in remote areas who work in the city

The translation methodology used in this study has been developed in other cross-cultural work in progress at the World Health Organization (WHO). It has two features which give it considerable advantage over straightforward forward translation/ back translation. First a bilingual group documents, discussing and resolving issues around the translation process. Second a monolingual group, with no knowledge of what the document looked like in its untranslated version, reads the translated document commenting on any aspect of the document which appears less than satisfactory in the language of the field centre.

In the Dutch centre the following individuals assisted in the translation process.

1. The bilingual group, consisted of three persons, namely Prof.dr. G.L. van Heck, Mrs. drs. J. de Vries, and Ms. drs. D. Hol. The first two of these individuals were familiar with the design and methodology of the project. The group was briefed by the principle investigator who was also the supervisor of this group. The members of the group were by virtue of their professional training familiar with issues in quality of life.
2. The monolingual group, consisted of five persons, who were able to comment on the translated document. Four of them had just a lower education. The names of these persons are: (1) Mrs. C.J. de Vries (2) Mr. L. de Vries (3) Mrs. A. van Putten and (4) Mr. C.F. van Putten. Because of their low education level, it was possible to see if the document was easy to read for every person. This was necessary because people with lower education had to read the document too. The fifth person who was in this group had studied the Dutch language. This person gave feedback about the linguistical aspects of the document. The name of the last person is Mrs. J. van Heck.
3. A professional translator. This person's name is Mrs. drs. L. Leroy. She works at the translation department of Philips Nederland.

The translation process had a number of steps. These are summarized below.

1. The original document was translated into Dutch by the supervisor of the bilingual group. This person had to keep in mind the population who would be asked to use the document. The translator consulted closely with an other member of the bilingual group in the translation process so that both translators were in agreement about the translation. The bilingual group then read through the document, discussed any further inconsistencies in the translation, and where appropriate amended these in the translated document.
2. A group of monolingual individuals then "tested" the document by reading it through. They looked for aspects of the translation which was not clearly comprehensible or were ambiguous in the target language. In the Dutch field centre the monolingual group operated exclusively in Dutch; there was no knowledge about the English version. Four members of the monolinguals had little formal education so that the comprehensibility of the document could be checked.
3. The bilingual group considered the comments of the monolingual group and incorporated these comments into the translated document only if they could be said to accurately reflect the meaning of the original document. This group insured that the document was clearly comprehensible and grammatically correct in the target language.
4. The translated document was then back-translated to the original language by a professional translator.
5. The original and back-translated documents were then reviewed by the group of bilingual experts, to determine the accuracy and equivalence of the translation process. The panel compared the original and back-translated document. If significant differences arose then the translation process had altered the meaning of the original document beyond acceptable variation.

It is not unusual for the majority of the document to be relatively stable in the two languages, although a few aspects are likely to show a degree of variation. Problems should be dealt with through further translation/ back-translation until a successful transfer of meaning is achieved. Wherever possible this should be done by the assembled bi-lingual panel. If equivalent, the translated document can then be accepted for use.

The supervisor of the bilingual group then prepared a summary report of the translation process.

This included a description of the individuals involved in the translation process, issues which arose in the translation and a copy of the back-translated document. This was then transmitted to WHO Geneva.

Welcome

The focus group moderator should welcome participants individually as they arrive. In the minutes before the focus group begins the moderator should engender informal discussion between the participants, but should avoid any discussion of the topic for the focus group (quality of life), or any divisive discussion which might make the participants feel different from one another (social class, politics ...).

It would be very helpful if visible first name labels could be distributed as participants arrive so that both the moderator and participants can refer to one another by first name.

Warm up

The focus group moderator introduces him or herself. In introducing him/herself the focus group moderator should be aware that the nature and extent of what they say about themselves will influence what the participants are likely to disclose about themselves, as well as the nature of the subsequent discussion. Participants should then introduce themselves.

Overview and topic

The moderator should seek to make a number of points.

The field centre is part of a cross-cultural project involving other centres around the world.

The group has been convened to seek people's views about the quality of life. It is, therefore, a very broad ranging topic of discussion which intimately affects all the participants and moderator(s).

The information arising from the group discussion is part of a larger project which aims to measure accurately the quality of life of a range of people.

The discussion will be used to arrive at a list of areas which the participants feel are important aspects of quality of life.

Ground rules

It is anticipated that the meeting will take about 90 minutes.

There are no right or wrong answers, but rather different points of view.

All participants' points of view are equally valuable, and participants share their point of view even if it differs from what others have said.

The discussion will be recorded so that a record of what was said is available. Stress confidentiality and the fact that the data will be used only for research purposes.

The questions**What are words or phrases which describe "quality of life"?**

The interviewer should guide the discussion to arrive at a communal meaning of what is meant by the term "quality of life". It may be an idea to ask participants to think about this for a minute or two before going around each participant in turn. This has a number of advantages. Everyone will have to think for themselves what is meant by quality of life before hearing what others have to say, everyone will have a chance to speak, and everyone will be reassured that their point of view is as valuable as other participants' points of view. After this a more general discussion can be encouraged.

This question is intended to get the discussion started and give participants an idea of what the topic of discussion is. As such the time spent on this question should be limited.

NOW SUMMARIZE

What are the things which affect people's quality of life? (45 minutes+)

Here the moderator should be seeking to arrive at a broad list of areas which the participants feel affect people's quality of life. One way to do this is to go around the group several times asking each individual to give an area until an exhaustive list seems to have been reached. After this the moderator should come back to each in turn to discuss it somewhat further. The moderator should be quite sure what participants mean by each area. By probing it will be possible for the moderator to be certain they have understood and will give them the information to provide a brief description of what is meant by each area mentioned by the participants.

NOW SUMMARIZE

Are there things that perhaps we have mentioned that you think are important to quality of life that people find it difficult to talk about?

Within the culture there may be some subjects that participants have already mentioned which they feel are difficult subjects to ask about in an interview or questionnaire (e.g. sex, bowel movements, health problems such as hemorrhoids). The focus group moderator should seek to find out if any of the facets which have been elicited would, in fact, be sensitive.

NOW SUMMARIZE

Are there things that perhaps we have not mentioned that you think are important to quality of life that people find it difficult to talk about?

This is an extension of the previous question but seeks to elicit any areas (facets) which are difficult to talk about but which have not yet been mentioned.

NOW SUMMARIZE

Are there any other important issues which have not been covered?

Here the moderator should see if the group feel that they have missed anything, or whether a particular member who has said relatively little has something more to contribute.

Summarize the major areas which have arisen in reply to the questions.

The moderator should attempt to summarize, with the help of a blackboard/flipchart, a list of areas (facets) which the group has generated. The moderator should be attuned to any spoken as well as non-verbal cues which suggest disagreement to the summary which the focus group moderator gives. If an assistant moderator has been involved in the focus group it may be very helpful if he/she summarizes what has been said whilst the moderator looks for agreement/disagreement.

Importance weightings

Once a list of areas (facets) is written up on the blackboard/flipchart the moderator should go through the list asking the participants to indicate about each of the areas (facets) whether it is "not so important", "important" or "very important" to the quality of life. This should be done through the consensual agreement of the group. Where the group is unable to reach agreement the moderator should make a note of this.

Are there more general levels which include some of the things you have mentioned which affect quality of life?

The moderator should guide the discussion to come up with a maximum of six very broad areas which contribute to quality of life. These broad areas are likely to include all the areas which have been discussed up to now. Participants should be encouraged to come up with very broad areas at this stage. Participants should be encouraged to say what they mean by these areas so that a brief description of each broad area can be written on the basis of the discussion.

It is possible that in the discussion up to this point the group will have mentioned some general levels, which the moderator should pick up on. "You mentioned X as one very general level which includes Y, Z and W. Can you think of any other broad areas like X?"

NOW SUMMARIZE

Closing

Any questions?

The moderator should then record about each focus group member their: age, sex, number of years they have spent in full-time education, and marital status.

Thank you

APPENDIX V Instruction for the pile sort task

This is an process that helps us to understand the relationships between the elements that people in many different cultures believe to be related to the positive and negative aspects of life.

Please look at all of the cards, and the words or phrases that appear on them. We would like for you to make piles or groupings of the cards, according to those that you believe are most closely related. You can use any criteria to place the cards together, or to separate them into different groupings.

You can make as many or as few piles as you wish. There are no correct or incorrect groupings; we are interested in your views about how these conditions are related to one another.

Once you have placed all of the cards together that you feel are related to one another, and have finished placing the cards in their appropriate groupings, please record the information on the accompanying form.

WHOQOL Pile Sort Data Recording Form

I. Demographic information

Name Sex Age
Education Occupation

II. Pile sort information

Pile	Card Number(s) in pile	Reason for placing cards in this pile
------	------------------------	---------------------------------------

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15

DEMOGRAPHIC INFORMATION OF FOCUS GROUP PARTICIPANTS
HEALTH PERSONNEL

Name:

Address:

Contact telephone number:

Age:

Sex: Male

Female

Highest education achieved:

Profession:

Marital status:

Would you like to make any comments on the focus group?

DEMOGRAPHIC INFORMATION FOCUS GROUP PARTICIPANTS
PATIENT POPULATION

Name:

Address:

Contact telephone number:

Age:

Sex: Male

Female

Highest education achieved:

Profession:

Marital status:

The organization you represent:

Would you like to make any comments on the focus group?

DEMOGRAPHIC INFORMATION FOCUS GROUP PARTICIPANTS
GENERAL POPULATION

Name:

Address:

Contact telephone number:

Age:

Sex: Male

Female

Highest education achieved:

Profession:

Marital status:

For caregivers only:

What is your relation with the person you care for?

What do you do for that person?

How long do you already care for the person?

Would you like to make any comments on the focus group?

APPENDIX VII Importance Rating Questionnaire

IMPORTANCE WEIGHTS

Please indicate how important you think each of the following areas is to your quality of life. For each issue indicate using the steps of the ladder how much this affects the quality of your life. If it is most important mark the step "Most important". If it is not important mark the step "Not important".

How important is "pain and discomfort" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "vitality and fatigue" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "sexual activity" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "sleep" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "motor functioning" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "mobility" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important are "sensory functions" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "thinking, learning, memory and concentration" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "happiness and contentment" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "depression" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "anxiety" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "hopefulness and optimism" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "self-esteem" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "self-efficacy" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "body image" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "ability to carry out activities of daily living" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "dependence on substances" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "communication capacity" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "working capacity" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "participation in and opportunity for recreation and pastimes" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "family support" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "support from friends/acquaintances" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "freedom, physical safety and security" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "quality of home environment" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "quality of work environment" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "work satisfaction" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important are "opportunities for acquiring information and skills" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "financial status" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "availability to and quality of health and social care" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "transport" to the quality of your life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

Thank you very much for your cooperation.

IMPORTANCE WEIGHTS HEALTH PERSONNEL

Please indicate how important you think each of the following areas is to the quality of life of your patients. For each issue indicate using the steps of the ladder how much this affects your patients' quality of life. If it is most important mark the step "Most important". If it is not important mark the step "Not important".

How important is "pain and discomfort" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "vitality and fatigue" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "sexual activity" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "sleep" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "motor functioning" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "mobility" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important are "sensory functions" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "thinking, learning, memory and concentration" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "happiness and contentment" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "depression" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "anxiety" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "hopefulness and optimism" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "self-esteem" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "self-efficacy" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "body image" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "ability to carry out activities of daily living" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "dependence on substances" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "communication capacity" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "working capacity" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "participation in and opportunity for recreation and pastimes" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "family support" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "support from friends/acquaintances" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "freedom, physical safety and security" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "quality of home environment" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "quality of work environment" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "work satisfaction" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important are "opportunities for acquiring information and skills" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "financial status" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "availability to and quality of health and social care" to your patients' quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

How important is "transport" to your patients quality of life?

Most important / Very important / Somewhat important / Neither important nor unimportant / Not important

Thank you very much for your cooperation.

APPENDIX VIII Item selection Dutch centre

Facet 1. Pain and discomfort

Self-reported objective	Self-reported subjective	Importance
Q1 Do you have pain? Q2 Do you have pain complaints? (ill group)	Q1 How do you experience pain? (ill group) Q2 Are you hindered by pain? (ill group) Q3 Is pain a hindrance to you? (professional group)	Q1 What means pain to you? (ill group) Q2 How do you experience pain? (professional group)
Q1 Heeft u pijn? Q2 Heeft u pijnklachten?	Q1 Hoe ervaart u pijn? Q2 Wordt u belemmerd door pijn? Q3 Belemmerd pijn u?	Q1 Wat betekent pijn voor u? Q2 Hoe beleeft u uw pijn?
The focus groups 3, 4, 6, A2, & A5 did not generate items at this level	The focus groups 3 tll 5, A2, A3, and A5 did not generate items at this level	Only the focus groups 5 & A4 generated items at this level

Facet 2. Vitality and fatigue

Self-reported objective	Self-reported subjective	Importance
Q1 Are you tired? ('well' group) Q2 Do you feel fit? (professional group) Q3 Are you bothered by fatigue? ('well' group)	Q1 How do you experience fatigue? ('well' group) Q2 Do you feel listless? ('well' group)	Q1 Do you find it important to be able to start the day full of energy? (panel) Q2 What means fatigue to you? (panel)
Q1 Bent u moe? Q2 Voelt u zich fit? Q3 Heeft u last van vermoeidheid?	Q1 Hoe ervaart u vermoeid? Q2 Voelt u zich lusteloos?	Q1 Vindt u het belangrijk dat u de dag vol energie kunt beginnen? Q2 Wat betekent vermoeidheid voor u?
Focus group 3 and all A's did not generate items at this level	Only the focus groups 2, 4, & A4 generated items at this level	The items are generated by the question writing panel

Facet 3. Sexual activity

Self-reported objective	Self-reported subjective	Importance
<p>Q1 How do you experience sexuality? ('well' group)</p> <p>Q2 Did you have unpleasant sexual experiences? (professional group)</p> <p>Q3 Do you have possibilities to be sexually active? (professional group)</p>	<p>Q1 Do you have problems with sexuality? (ill group)</p> <p>Q2 Are you satisfied with your sexual activity? (ill & 'well' group)</p> <p>Q3 Is your sexual activity: (un)satisfying (professional group)</p>	<p>Q1 How important is sexual activity for you? (professional group)</p> <p>Q2 What place does sex have in your life? (professional group)</p> <p>Q3 What value do you attach to sexual activity? (ill group)</p>
<p>Q1 Hoe beleeft u seksualiteit?</p> <p>Q2 Heeft u nare seksuele ervaringen gehad?</p> <p>Q3 Heeft u mogelijkheden om seksueel actief te zijn?</p> <p>Only the focus groups 2, 5, & 6 generated items at this level</p>	<p>Q1 Heeft u problemen met seksualiteit?</p> <p>Q2 Bent u tevreden met uw seksuele activiteit?</p> <p>Q3 Is uw seksuele activiteit: (on)bevredigend</p> <p>Only focus group 6 and all A's did not generate items at this level</p>	<p>Q1 Hoe belangrijk is seksuele activiteit voor u?</p> <p>Q2 Welke plaats neemt sex in uw leven in?</p> <p>Q3 Welke waarde hecht u aan seksuele activiteit?</p> <p>Only focus group 5 and A4 generated items at this level</p>

Facet 4. Sleep

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Do you sleep? (ill group)</p> <p>Q2 Are you able to sleep? ('well' group)</p> <p>Q3 How do you sleep? too little - too much (professional group)</p>	<p>Q1 Do you have problems with sleeping? (professional group)</p> <p>Q2 How do you experience your sleep? (panel)</p> <p>Q3 How do you feel when you are awake? (professional group)</p>	<p>Q1 How important is sleep to you? (professional group)</p> <p>Q2 What value do you attach to sleep? (professional group)</p> <p>Q3 Is sleep important to you? (ill group)</p>
<p>Q1 Slaapt u?</p> <p>Q2 Kunt u slapen?</p> <p>Q3 Hoe slaapt u? te weinig - te veel</p> <p>The focus groups 1, 2, 5, & A2 generated items at this level</p>	<p>Q1 Heeft u problemen met slapen?</p> <p>Q2 Hoe ervaart u uw slaap?</p> <p>Q3 Hoe voelt u zich als u wakker wordt?</p> <p>Focus group 5 and the question writing pane generated items at this level</p>	<p>Q1 Hoe belangrijk is slaap voor u?</p> <p>Q2 Welke waarde hecht u aan slaap?</p> <p>Q3 Is slaap belangrijk voor u?</p> <p>Only focus group 5 and A4 generated items at this level</p>

Facet 5. Motor functioning

Self-reported objective	Self-reported subjective	Importance
Q1 Do you have control over your own movements? Q2 Does your body let you down? (ill group) Q3 Are you able to move everything normally? (ill group)	Q1 Do you have problems with motor functioning? (ill group) Q2 Are you satisfied with the control you have over your own body? ('well' & professional group)	Q1 Having control over my own movements is? (un)important (panel) Q2 What means having control over your own movements to you? (panel)
Q1 Heeft u controle over uw eigen bewegingen? Q2 Laat uw lichaam u in de steek? Q3 Kunt u alles normaal bewegen?	Q1 Heeft u problemen met motorisch functioneren? Q2 Bent u tevreden met de controle die u heeft over uw lichaam?	Q1 Het hebben van controle over mijn bewegingen is? (on)belangrijk Q2 Wat betekent het hebben van controle over uw eigen bewegingen voor u?
A5 did not generate items at this level	Only the focus groups 1, 2, & 5 generated items at this level	The items are generated by the question writing panel

Facet 6. Mobility

Self-reported objective	Self-reported subjective	Importance
Q1 Are you able to move on? (panel) Q2 Are you hindered in your locomotion? (panel)	Q1 Do you have problems with moving on? (ill group) Q2 Do you feel restricted in your movements? ('well' group) Q3 Are you satisfied with the way you are able to move on? (panel)	Q1 Do you find it important to be able to move on? (panel) Q2 What means locomotion to you? (ill group) Q3 Is locomotion important to you? (ill group)
Q1 Kunt u zich voortbewegen? Q2 Wordt u belemmerd in uw voortbewegen?	Q1 Heeft u problemen met zich voortbewegen? Q2 Voelt u zich beperkt in uw bewegingen? Q3 Bent u tevreden over de wijze waarop u zich kunt voortbewegen?	Q1 Vindt u het belangrijk zich te kunnen voortbewegen? Q2 Wat betekent zich kunnen voortbewegen voor u? Q3 Is zich kunnen voortbewegen belangrijk voor u?
The focus groups 1, 4, & the question writing panel generated items at this level	The focus groups 3, 5, & all A's did not generate items at this level	Only focus group 5, A4, & the question writing panel generated items at this level

Self-reported objective	Self-reported subjective	Importance
Q1 Are you able to use your senses? (ill group)	Q1 Are you satisfied with your senses? (ill & professional group) Q2 Are you restricted by your senses? (panel)	Q1 How important are your senses to you? (panel)
Q1 Kunt u uw zintuigen gebruiken?	Q1 Bent u tevreden met uw zintuigen? Q2 Wordt u beperkt door uw zintuigen?	Q1 Hoe belangrijk zijn uw zintuigen voor u?
Only focus group 1 generated an item at this level	The focus groups 1,2, 5, & the question writing panel generated items at this level	The item was generated by the question writing panel

Facet 8. Thinking, learning, memory, and concentration

Self-reported objective	Self-reported subjective	Importance
Q1 Are you able to concentrate? ('well' & professional group) Q2 My memory functions? (professional group) Q3 Are you able to formulate your thoughts clearly? (professional group)	Q1 Does it irritate you when you forget something? ('well' group) Q2 Are you satisfied with your intellectual capacity? (professional group) Q3 Are you satisfied with your ability to concentrate? (professional group)	Q1 What means thinking to you? (ill group) Q2 What means learning to you? (ill group) Q3 What means a good memory to you? (ill group) Q4 What means concentration to you? (ill group)
Q1 Kunt u zich concentreren? Q2 Mijn geheugen functioneert? Q3 Kunt u uw gedachten helder formuleren?	Q1 Irriteert het u als u iets vergeten bent? Q2 Bent u tevreden met uw denkvermogen? Q3 Bent u tevreden met uw concentratievermogen?	Q1 Wat betekent denken voor u? Q2 Wat betekent leren voor u? Q3 Wat betekent een goed geheugen voor u? Q4 Wat betekent concentratie voor u?
The focus groups 1, 2, & 5 generated the items at this level	The focus groups 4 & 5 generated the items at this level	A4 generated the items at this level

Facet 9. Happiness and contentment

Self-reported objective	Self-reported subjective	Importance
Q1 Are you satisfied with your life? Q2 Are you happy? ('well' & professional group) Q3 Do you fancy life? ('well' group)	Q1 Are you a content person? Q2 Do you enjoy your life? (professional group)	Q1 What means happiness and contentment to you? (panel)
Q1 Bent u tevreden met uw leven? Q2 Bent u gelukkig? Q3 Heeft u zin in het leven?	Q1 Bent u een tevreden mens? Q2 Geniet u van uw leven?	Q1 Wat betekent geluk en tevredenheid voor u?
A2, A3, & A5 did not generate items at this level	The focus groups 1, 2, 4, & 5 generated items at this level	The items is generated by the question writing panel

Facet 10. Depression

Self-reported objective	Self-reported subjective	Importance
Q1 Do you feel low? (ill group) Q2 Are you down? (ill & professional group) Q3 Are suffering from a black mood? (panel)	Q1 Do you find your situation a dead end? ('well' group) Q2 Are you feeling dejected? ('well' group)	Q1 In the dumps? controls my life - plays no role in my life (panel) Q2 What means being down to you? (ill group)
Q1 Zit u in de put? Q2 Bent u neerslachtig? Q3 Heeft u last van sombere buien?	Q1 Vindt u uw situatie uitzichtloos? Q2 Voelt u zich moedeloos?	Q1 Somberheid? overheerst mijn leven - speelt geen rol in mijn leven Q2 Wat betekent neerslachtigheid voor u?
The focus groups 3, 4, & A5 did not generate items at this level	Only the focus groups 2 & 4 generated items at this level	Only A4 & the question writing panel generated items at this level

Self-reported objective	Self-reported subjective	Importance
Q1 Are you afraid? Q2 Are you insecure? (panel) Q3 Are you anxious? (ill group)	Q1 Does anxiety restrict you? ('well' group)	Q1 What means anxiety to you? (ill group) Q2 What means anxiety in your life? (panel)
Q1 Bent u bang? Q2 Bent u onzeker? Q3 Bent u angstig?	Q1 Beperkt angst u?	Q1 Wat betekent angst voor u? Q2 Wat betekent angst in uw leven?
Focus group 3, A3 and A5 did not generate items at this level	Only focus group 4 generated an item at this level	The items are generated by the question writing panel and A4

Self-reported objective	Self-reported subjective	Importance
Q1 Do you have plans for the future? ('well' group) Q2 How do you view your own future? ('well' group) Q3 Are you optimistic? (panel)	Q1 What do you expect of your life? (ill & 'well' group) Q2 What do you expect of the future? (ill & professional group)	Q1 Hope makes life. ('well' & professional group) Q2 While there's hope, there's life. ('well' & professional group)
Q1 Heeft u toekomstplannen? Q2 Hoe ziet u uw eigen toekomst? Q3 Bent u optimistisch?	Q1 Wat verwacht u van uw leven? Q2 Wat verwacht u van de toekomst?	Q1 Hoop doet leven. Q2 Zolang er hoop is, is er leven.
The focus groups 1,2,4, A3, & the question writing panel generated the items at this level	The focus groups 4,6, & A4 generated items at this level	Only the focus groups 2 & 5 generated items at this level

Facet 13. Self-esteem

Self-reported objective	Self-reported subjective	Importance
<p>Q1 How do you think about yourself? (ill group) Q2 Are you proud at yourself? (ill group) Q3 Do you have appreciation for yourself? ('well' group)</p> <p>Q1 Hoe denkt u over uzelf? Q2 Bent u trots op uzelf? Q3 Heeft u waardering voor uzelf?</p> <p>The focus groups 1 to 4 generated the items at this level</p>	<p>Q1 To what extent do you value yourself? ('well' group) Q2 Are you satisfied with the things you can do? (ill group)</p> <p>Q1 In welke mate waardeert u uzelf? Q2 Bent u tevreden met hetgeen u kunt presteren?</p> <p>The focus groups 1,2, & A3 generated the items at this level</p>	<p>Q1 What means self-esteem to you? (panel) Q2 Self-esteem is? (un)important (panel)</p> <p>Q1 Wat betekent zelfwaardering voor u? Q2 Zelfwaardering is? (on)belangrijk</p> <p>Items are written by the question writing panel</p>

Facet 14. Self-efficacy

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Do you have confidence in yourself? (professional group) Q2 Do the things you want succeed? (panel) Q3 Can you realise the goals you formulate yourself? (ill group)</p> <p>Q1 Heeft u vertrouwen in uzelf? Q2 Lukken de dingen die u wilt? Q3 Kunt u de doelen die u zelf formuleert realiseren?</p> <p>The focus groups 1, 2, 5, A4, & the question writing panel generated the items at this level</p>	<p>Q1 Do you feel able to finish what you started? (professional group)</p> <p>Q1 Voelt u zich in staat om af te maken waaraan u begint?</p> <p>Only the focus groups 1 & 5 generated items at this level</p>	<p>Q1 How important is self-efficacy to you? (panel)</p> <p>Q1 Hoe belangrijk is geloof in eigen kunnen voor u?</p> <p>Generated by the question writing panel</p>

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Are you ashamed of your own body? (panel)</p> <p>Q2 Do you look at yourself in the mirror? (panel)</p> <p>Q3 Do you find that you are looking good? (professional group)</p>	<p>Q1 Are you satisfied with your own body? (ill & professional group)</p> <p>Q2 Are you satisfied with the way you look? ('well' & professional group)</p> <p>Q3 How do you see your body? (ill group)</p>	<p>Q1 How important is it to be satisfied with your own body? ('well' group)</p>
<p>Q1 Schaamt u zich voor uw eigen lichaam?</p> <p>Q2 Kijkt u naar uzelf in de spiegel?</p> <p>Q3 Vindt u dat u er goed uitziet?</p>	<p>Q1 Bent u tevreden over uw lichaam?</p> <p>Q2 Bent u tevreden met uw uiterlijk?</p> <p>Q3 Hoe ziet u uw lichaam?</p>	<p>Q1 Hoe belangrijk is het om tevreden te zijn met uw eigen lichaam?</p>
<p>Only the focus groups 3 & 5 generated items at this level</p>	<p>The focus groups 3, 4, A2, & A5 did not generate items at this level</p>	<p>Focus group 2 generated the item at this level</p>

Facet 16. Ability to carry out activities of daily living

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Are you able to carry out the activities of daily living that you want to do?</p> <p>Q2 How is your ability to carry out activities of daily living? (ill group)</p> <p>Q3 Are you able to take care of yourself? ('well' group)</p>	<p>Q1 Are you satisfied with your ability to carry out activities of daily living? (professional group)</p> <p>Q2 How do you experience your own ability to carry out activities of daily living? (professional group)</p>	<p>Q1 Does it bother you when you are not able to carry out activities of daily living? ('well' group)</p> <p>Q2 Is carrying out activities of daily living important to you? (ill group)</p>
<p>Q1 Bent u in staat om alledaagse activiteiten die u wilt te verrichten?</p> <p>Q2 Hoe is uw vermogen om alledaagse activiteiten te verrichten?</p> <p>Q3 Bent u in staat om voor uzelf te zorgen?</p>	<p>Q1 Bent u tevreden met uw vermogen om alledaagse activiteiten te verrichten?</p> <p>Q2 Hoeervaart u uw vermogen om alledaagse activiteiten te verrichten?</p>	<p>Q1 Zit het u dwars wanneer u alledaagse activiteiten niet kunt verrichten?</p> <p>Q2 Is het verrichten van alledaagse activiteiten belangrijk voor u?</p>
<p>The focus groups 1,5, & A2 to A5 did not generate items at this level</p>	<p>Only focus group 5 generated items at this level</p>	<p>Only the focus groups 2 & 3 generated items at this level</p>

Facet 17. Dependence on substances

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Are you dependent on alcohol, tobacco, drugs, or medicine? ('well' group)</p> <p>Q2 Can you refrain from alcohol, tobacco, drugs, or medicine? ('well' group)</p> <p>Q3 Can you do without alcohol, tobacco, drugs, or medicine? (professional group)</p>	<p>Q1 Does it bother you that you are dependent on alcohol, tobacco, drugs, or medicine? ('well' group)</p> <p>Q2 How do you experience your dependency on alcohol, tobacco, drugs, or medicine? (ill group)</p>	<p>Q1 Does your dependency on alcohol, tobacco, drugs, or medicine control your life? (professional group)</p>
<p>Q1 Bent u afhankelijk van alcohol, tabak, drugs of medicijnen?</p> <p>Q2 Kunt u buiten alcohol, tabak, drugs of medicijnen?</p> <p>Q3 Kunt u zonder alcohol, tabak, drugs of medicijnen?</p>	<p>Q1 Zit het u dwars dat u afhankelijk bent van alcohol, tabak, drugs of medicijnen?</p> <p>Q2 Hoe ervaart u uw afhankelijk van alcohol, tabak, drugs of medicijnen?</p>	<p>Q1 Beheerst uw afhankelijkheid van alcohol, tabak, drugs of medicijnen uw leven?</p>
<p>The focus groups 2, 5, 6, & A3 generated the items at this level</p>	<p>The focus groups 2 & 3 generated the items at this level</p>	<p>Only focus group 5 generated an item at this level</p>

Facet 18. Communication capacity

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Can you make your intentions clear to others? ('well' group)</p> <p>Q2 Can you make clear what you mean? ('well' & professional group)</p> <p>Q3 Do you have problems with reading, writing, or speaking? (professional group)</p>	<p>Q1 Are you satisfied with your communication capacity? (professional group)</p> <p>Q2 Do you have the feeling that you are understood? (ill group)</p>	<p>Q1 How important is it for you to make your wishes and intentions clear to others? ('well' group)</p> <p>Q2 What means communication to you? (ill group)</p>
<p>Q1 Kunt u uw bedoelingen aan anderen duidelijk maken?</p> <p>Q2 Kunt u duidelijk maken wat u bedoelt?</p> <p>Q3 Heeft u problemen met lezen, schrijven of spreken?</p>	<p>Q1 Bent u tevreden met uw communicatievermogen?</p> <p>Q2 Heeft u het gevoel dat u begrepen wordt?</p>	<p>Q1 Hoe belangrijk is het voor u om uw wensen en bedoelingen aan anderen duidelijk te maken?</p> <p>Q2 Wat betekent communicatie voor u?</p>
<p>All A's did not generate items at this level</p>	<p>Only focus group 5 and A3 generated items at this level</p>	<p>Only focus group 2 and A4 generated items at this level</p>

Facet 19. Working capacity

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Are you capable of doing your work? (panel)</p> <p>Q2 Are you able to carry out work? (panel)</p> <p>Q3 Do your duties coincide with your abilities? ('well' group)</p>	<p>Q1 Do you feel able to carry out your duties? ('well' group)</p> <p>Q2 Do you feel able to carry out the duties that you have to fulfill? ('well' group)</p>	<p>Q1 Being able to work is? (un)important (panel)</p> <p>Q2 Not being able to work is? (panel)</p> <p>Q3 What means work capacity to you? (ill group)</p>
<p>Q1 Bent u in staat om uw werkzaamheden te doen?</p> <p>Q2 Kunt u werkzaamheden verrichten?</p> <p>Q3 Komen uw werkzaamheden overeen met wat u kunt?</p>	<p>Q1 Voelt u zich in staat om werkzaamheden te verrichten?</p> <p>Q2 Voelt u zich in staat om de werkzaamheden te volbrengen die u moet doen?</p>	<p>Q1 Kunnen werken is?</p> <p>Q2 Niet kunnen werken is?</p> <p>Q3 Wat betekent werkvermogen voor u?</p>
<p>The focus groups 2,4,5, A1, A3, & the question writing panel generated items at this level</p>	<p>Only focus group 4 generated items at this level</p>	<p>Focus group 6, A4 and the question writing panel generated items at this level</p>

Facet 20. Participation in and opportunity for recreation and pastimes

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Do you have opportunities for recreation? (ill group)</p> <p>Q2 Do you have opportunities for hobbies? (ill group)</p> <p>Q3 Can you practice your hobbies? (ill group)</p>	<p>Q1 Do your hobbies relax you? ('well' group)</p> <p>Q2 Are you satisfied with your recreation? (professional group)</p> <p>Q3 Are you satisfied with your hobbies? (professional group)</p>	<p>Q1 No one can do without relaxation. (panel)</p> <p>Q2 What mean hobbies to you? (ill group)</p> <p>Q3 What means participation in recreation to you? (ill group)</p>
<p>Q1 Heeft u mogelijkheden tot recreatie?</p> <p>Q2 Heeft u mogelijkheden tot hobbies?</p> <p>Q3 Kunt u uw hobbies uitoefenen?</p>	<p>Q1 Geven uw hobbies u ontspanning?</p> <p>Q2 Bent u tevreden met uw recreatie?</p> <p>Q3 Bent u tevreden met uw hobbies?</p>	<p>Q1 Geen mens kan zonder ontspanning.</p> <p>Q2 Wat betekenen hobbies voor u?</p> <p>Q3 Wat betekent het deelnemen in recreatie voor u?</p>
<p>The focus groups 5, A1,A4, & A5 did not generate items at this level</p>	<p>The focus groups 4 & 5 generated items at this level</p>	<p>Only A4 & the question writing panel generated items at this level</p>

Facet 21. Isolation/social contact

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Do you have contact with others? ('well' & professional group)</p> <p>Q2 What is the nature of the contact with others? (panel)</p> <p>Q3 Are you alone? always - never (professional)</p>	<p>Q1 Are you satisfied with the contacts you have with others? ('well' group)</p> <p>Q2 Do you feel lonely? (ill & professional group)</p> <p>Q3 Do you have enough social contacts? (professional group)</p>	<p>Q1 Do you need contact with others? ('well' group)</p> <p>Q2 How important is social contact to you? ('well' group)</p> <p>Q3 What means social contact to you? (ill group)</p>
<p>Q1 Heeft u contact met anderen?</p> <p>Q2 Wat is de aard van het contact met anderen?</p> <p>Q3 Bent u alleen? altijd - nooit</p>	<p>Q1 Bent u tevreden met de contacten die u met andere heeft?</p> <p>Q2 Voelt u zich eenzaam?</p> <p>Q3 Heeft u voldoende sociale contacten?</p>	<p>Q1 Heeft u behoefte aan contact met anderen?</p> <p>Q2 Hoe belangrijk is sociaal contact voor u?</p> <p>Q3 Wat betekent sociaal contact voor u?</p>
<p>The focus groups 4, A4, & A5 did not generate items at this level</p>	<p>The focus groups 2,3,4, & 5 generated items at this level</p>	<p>Focus group 2 and A4 generated items at this level</p>

Facet 22. Family support

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Do you receive support from your family? (ill group)</p> <p>Q2 Do you get support from your family? (ill group)</p> <p>Q3 Can you come knocking for help with your family? always - never (professional group)</p>	<p>Q1 How do you experience the support from your family? (panel)</p> <p>Q2 Do you feel supported by your family? (professional group)</p>	<p>Q1 Is support from family important to you? (ill & 'well' group)</p> <p>Q2 Do you need support from your family? ('well' group)</p> <p>Q3 Do you attach value to support from family? (panel)</p>
<p>Q1 Ontvangt u steun van uw familie?</p> <p>Q2 Krijgt u steun van uw familie?</p> <p>Q3 Kunt u om hulp bij uw familie aankloppen? altijd - nooit</p>	<p>Q1 Hoe ervaart u de steun van uw familie?</p> <p>Q2 Voelt u zich gesteund door uw familie?</p>	<p>Q1 Is steun van familie belangrijk voor u?</p> <p>Q2 Heeft u behoefte aan steun van uw familie?</p> <p>Q3 Hecht u waarde aan steun van uw familie?</p>
<p>The focus groups 5, A1,A2,A4, & A5 did not generate items at this level</p>	<p>Focus group 5 and the question writing panel generated items at this level</p>	<p>The focus groups 2, A4, & the question writing panel generated items at this level</p>

Facet 23. Support from friends/acquaintances

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Do you get support from friends and acquaintances? (panel)</p> <p>Q2 Do you receive support from friends and acquaintances? (ill group)</p> <p>Q3 Can you come knocking for help with your friends and acquaintances? (professional group)</p>	<p>Q1 Do you feel supported by your friends and acquaintances? (professional group)</p> <p>Q2 Do you experience support from friends and acquaintances? (professional group)</p>	<p>Q1 Do you attach value to support from your friends and acquaintances? (panel)</p> <p>Q2 Is support from friends and acquaintances important to you? (ill & 'well' group)</p> <p>Q3 Do you need support from friends and acquaintances? ('well' group)</p>
<p>Q1 Krijgt u steun van vrienden en kennissen?</p> <p>Q2 Ontvangt u steun van vrienden en kennissen?</p> <p>Q3 Kunt u om hulp bij vrienden en kennissen aankloppen?</p>	<p>Q1 Voelt u zich gesteund door vrienden en kennissen?</p> <p>Q2 Ervaart u steun van vrienden en kennissen?</p>	<p>Q1 Hecht u waarde aan steun van uw vrienden en kennissen?</p> <p>Q2 Is steun van vrienden en kennissen belangrijk voor u?</p> <p>Q3 Heeft u behoefte aan steun van vrienden en kennissen?</p>
<p>The focus groups 3,4,6, & A3 and the question writing panel generated items at this level</p>	<p>The focus groups 5 & 6 generated items at this level</p>	<p>Focus group 2, A4, & the question writing panel generated items at this level</p>

Facet 24. Activities as provider/supporter

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Are you lending support to others? (panel)</p> <p>Q2 Do you give support? (ill group)</p>	<p>Q1 How do you experience giving support? ('well' group)</p> <p>Q2 Is giving support aggravating? (ill group)</p> <p>Q3 Do you mean much for other people? (professional group)</p>	<p>Q1 Giving support to others gives you self-esteem. ('well' group)</p> <p>Q2 Do you find it important to give support? (ill group)</p> <p>Q3 What means giving support to you? (ill group)</p>
<p>Q1 Bent u een steun voor anderen?</p> <p>Q2 Verleent u steun?</p>	<p>Q1 Hoeervaart u het geven van steun?</p> <p>Q2 Is het geven van steun belastend voor u?</p> <p>Q3 Betekent u veel voor andere mensen?</p>	<p>Q1 Steun geven aan anderen geeft je zelfwaardering.</p> <p>Q2 Vindt u het belangrijk om steun te geven?</p> <p>Q3 Wat betekent het geven van steun voor u?</p>
<p>The focus groups 3,5,6, & the question writing panel generated items at this level</p>	<p>The focus groups 2,3,5, & the question writing panel generated items at this level</p>	<p>Focus group 2 and A4 generated items at this level</p>

Facet 25.

Religion

Self-reported objective	Self-reported subjective	Importance
Q1 Are you religious? (panel) Q2 Do you have a faith? (ill group) Q3 Does religion have an influence on your life? (ill group)	Q1 Do you have support from your religion? (panel) Q2 Do you find support in your religious conviction? (ill group) Q3 Do you find comfort in your religious conviction? (ill group)	Q1 Religion gives you certainty. ('well' group) Q2 Religion gives a meaning to your life. ('well' group) Q3 Is religion important to you? (ill group)
Q1 Bent u godsdienstig? Q2 Heeft u een geloof? Q3 Heeft religie invloed op uw leven?	Q1 Heeft u steun aan uw geloof? Q2 Vindt u steun in uw geloofsovertuiging? Q3 Vindt u troost in uw geloofsovertuiging?	Q1 Religie geeft u zekerheid. Q2 Religie geeft zin aan uw leven. Q3 Is geloof belangrijk voor u?
The focus groups 3.6, A3, & the question writing panel generated items at this level	Focus group 3, A3, & the question writing panel generated items at this level	The focus groups 2,4,5, & A4 generated items at this level

Facet 26.

Freedom, physical safety and security

Self-reported objective	Self-reported subjective	Importance
Q1 Do you feel insecure and threatened? ('well' & professional group) Q2 Do you dare alone on the street? (ill group) Q3 Do you feel free to do whatever you want to do? (ill & professional group)	Q1 Do you feel vulnerable? (ill group) Q2 Are you satisfied with you freedom? (panel) Q3 Are you satisfied with your safety? (panel)	Q1 Security is for me? (panel) Q2 What means freedom to you? (ill group) Q3 What means safety to you? (ill group)
Q1 Voelt u zich onveilig en bedreigd? Q2 Durft u alleen de straat op? Q3 Voelt u zich vrij om te doen en laten wat u wilt?	Q1 Voelt u zich kwetsbaar? Q2 Bent u tevreden over uw vrijheid? Q3 Bent u tevreden over uw veiligheid?	Q1 Geborgenheid is voor mij? Q2 Wat betekent vrijheid voor u? Q3 Wat betekent veiligheid voor u?
The focus groups 2 to 6 generated items at this level	The focus groups 2,3, & the question writing panel generated items at this level	A4 & the question writing panel generated items at this level

Facet 27. Quality of home environment

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Does your home environment offer you security? ('well' group)</p> <p>Q2 Does your home environment offer you comfort? (professional group)</p> <p>Q3 Does your home environment offer you privacy? (panel)</p>	<p>Q1 Do you like it where you live? (ill group)</p> <p>Q2 Are you satisfied with your living conditions? (ill group)</p> <p>Q3 Are you satisfied with your accommodation? (professional group)</p>	<p>Q1 How important is your home environment to you? (ill group)</p>
<p>Q1 Biedt uw woonomgeving u geborgenheid?</p> <p>Q2 Biedt uw woonomgeving u gemak en comfort?</p> <p>Q3 Biedt uw woonomgeving u privacy?</p> <p>The focus groups 2,4,5,6, & the question writing panel generated items at this level</p>	<p>Q1 Vindt u het prettig waar u woont?</p> <p>Q2 Bent u tevreden met uw leefomstandigheden?</p> <p>Q3 Bent u tevreden met uw huisvesting?</p> <p>The focus groups 2 to 5, A3, A5 generated items at this level</p>	<p>Q1 Hoe belangrijk is uw woonomgeving voor u?</p> <p>A1 generated the item at this level</p>

Facet 28. Quality of work environment

Self-reported objective	Self-reported subjective	Importance
<p>Q1 Is your work environment adapted to you? (ill group)</p> <p>Q2 Your work environment is? (un) comfortable ('well' group)</p>	<p>Q1 Are you satisfied with the situation you work under? (ill & 'well' group)</p> <p>Q2 Do you feel pleasant at your workplace? ('well' group)</p> <p>Q3 Are you satisfied with the circumstances under which you carry out your daily work? (ill group)</p>	<p>Q1 How important is your work environment to you? (ill group)</p>
<p>Q1 Is uw werkomgeving aan u aangepast?</p> <p>Q2 Uw werkomgeving is? (on) comfortabel</p> <p>The focus groups 3 & 4 generated items at this level</p>	<p>Q1 Bent u tevreden met uw werksituatie?</p> <p>Q2 Voelt u zich prettig op uw werkplek?</p> <p>Q3 Bent u tevreden met de omstandigheden waaronder u uw dagelijkse werkzaamheden moet verrichten?</p> <p>The focus groups 2, 3, A3, A4, & the question writing panel generated items at this level</p>	<p>Q1 Hoe belangrijk is uw werkomgeving voor u?</p> <p>A1 generated the item at this level</p>

Self-reported objective	Self-reported subjective	Importance
Q1 Can you get where you want to go? (ill & professional group) Q2 Do you have transport? (ill group) Q3 Are you chained to the house? ('well' group)	Q1 Do you feel restricted in the possibilities to move yourself? ('well' group) Q2 Are you satisfied with your transport? ('well' & professional group)	Q1 What means transport to you? (ill group) Q2 How important is transport to you? (ill group)
Q1 Kunt u overal komen waar u heen wilt? Q2 Heeft u vervoer? Q3 Bent u aan huis gekluisterd?	Q1 Voelt u zich beperkt in de mogelijkheden om u te verplaatsen? Q2 Bent u tevreden met uw vervoer?	Q1 Wat betekent vervoer voor u? Q2 Hoe belangrijk is vervoer voor u?
The focus groups 1, 3, 4, 5, & the question writing panel generated items at this level	The focus groups 2, 4, 5, & 6 generated items at this level	Focus group 3 and A1 generated items at this level

Questions should:

1. Be based as far as possible on the suggestions of patients and health personnel participating in the focus groups.
2. Give rise to answers which are illuminating about the respondents' quality of life, as defined in this project.
3. Reflect the meaning conveyed in the facet definition.
4. Cover, in combination with other questions for a given facet, the key aspects of that facet as described in the facet definition.
5. Use simple language, avoiding ambiguity in terms of either wording or phraseology.
6. Be shorter rather than longer.
7. Avoid double negatives.
8. Be amenable to a rating scale.
9. Enquire about a single issue/facet.
10. Avoid any explicit reference point either in terms of time or in terms of some comparison point (e.g., the ideal or before I was ill).
11. Be applicable to individuals with a range of impairment.
12. Be phrased as questions and not statements.
13. Reflect the typology of questions adopted for the project.

APPENDIX X WHOQOL Global Question Pool

Facet 0: Overall Quality of Life and General Health

Perceived objective

- G1.1 How would you rate your quality of life?
- G1.2 How is your health?

Self-report subjective

- G2.1 How satisfied are you with the quality of your life?
- G2.2 In general, how satisfied are you with your life?
- G2.3 How satisfied are you with your health?

DOMAIN I: PHYSICAL HEALTH

Facet 1: Pain and Discomfort

Perceived objective

- F1.1.1 How often do you suffer (physical) pain?
- F1.1.2 Do you feel any (physical) pain?
- F1.1.3 How easily are you able to get relief from pain?

Self-report subjective

- F1.2.3 Do you worry about your pain or discomfort?
- F1.2.2 How afraid are you of experiencing (physical) pain?
- F1.2.3 How difficult is it for you to handle any pain or discomfort?
- F1.2.4 Do you feel that pain or discomfort limits you life?
- F1.2.5 To what extent do you feel that (physical) pain prevents you from doing what you need to do?

Facet 2: Energy and Fatigue

Perceived objective

- F2.1.1 Do you have enough energy for everyday life?
- F2.1.2 To what extent do you have the energy to do what you need to do?
- F2.1.3 How easily do you get tired?
- F2.1.4 How much of the time do you feel tired?

Self-report subjective

- F2.2.1 How satisfied are you with the energy that you have?
- F2.2.2 How satisfied are you with the energy you have to do what you need to do?
- F2.2.3 How satisfied are you with the energy you have to do what you want to do?
- F2.2.4 How much are you bothered by fatigue?
- F2.2.5 How much do you feel that fatigue affects your daily life?

Facet 3: Sexual Activity

Perceived objective

- F3.1.1 How would you rate your sex life?
- F3.1.2 How well are your sexual needs fulfilled?
- F3.1.3 Is your sexual life a concern to you?
- F3.1.4 Do you have problems with your sex life?

Self-report subjective

- F3.2.1 How satisfied are you with your sex life?
- F3.2.2 How satisfied are you with the sexual aspects of your life?
- F3.2.3 Are you bothered by any difficulties in your sex life?

Facet 4: Sleep and Rest

Perceived objective

- F4.1.1 How well do you sleep?
- F4.1.2 How refreshed do you feel after sleeping?
- F4.1.3 Do you have any difficulties with sleeping?

Self-report subjective

- F4.2.1 How satisfying is your sleep?
- F4.2.2 How satisfied are you with your sleep?
- F4.2.3 How much do any sleep problems worry you?
- F4.2.4 Do you feel that sleep problems interfere with your everyday activities?

Facet 5: Sensory Functions

Perceived objective

F5.1.1 How well do you hear?

F5.1.2 How well do you see?

Self-report subjective

F5.2.1 How satisfied are you with your sight?

F5.2.2 Do you feel that any vision problems interfere with performing everyday activities?

F5.2.3 Does any impairment in sight interfere with your enjoyment of life?

F5.2.4 How satisfied are you with your hearing?

F5.2.5 How much do you feel any hearing problems interfere with performing everyday activities?

DOMAIN II: PSYCHOLOGICAL HEALTH

Facet 6: Positive Feelings

Perceived objective

F6.1.1 How happy are you?

F6.1.2 How much do you enjoy life?

F6.1.3 Do you generally feel content?

F6.1.4 How positive do you feel about the future?

F6.1.5 Do you see the future with hope and optimism?

F6.1.6 How much do you experience positive feelings in your life?

Self-report subjective

F6.2.1 How satisfied are you with your level of happiness?

F6.2.2 How satisfied are you with your level of contentment?

F6.2.3 How worried are you about what the future holds for you?

Facet 7: Thinking, Learning, Memory, and Concentration

Perceived objective

F7.1.1 Do you have the ability to remember things?

F7.1.2 How is your memory?

F7.1.3 How would you rate your memory?

F7.1.4 How would you rate your ability to think through everyday problems?

F7.1.5 Is your thinking clear?

F7.1.6 How well are you able to concentrate?

Self-report subjective

F7.2.1 How satisfied are you with your ability to learn new information?

F7.2.2 How satisfied are you with your memory?

F7.2.3 How satisfied are you with your ability to make decisions?

F7.2.4 How satisfied are you with your ability to think?

F7.2.5 How satisfied are you with your concentration?

Facet 8: Self-esteem

Perceived objective

F8.1.1 How much do you value yourself?

F8.1.2 How do you feel about yourself?

F8.1.3 How much confidence do you have in yourself?

F8.1.4 Do you regard yourself as worthy of respect from others?

Self-report subjective

F8.2.1 How satisfied are you with yourself?

F8.2.2 How satisfied are you with your abilities?

F8.2.3 How satisfied are you with the respect you get from others?

Facet 9: Body Image and Appearance

Perceived objective

F9.1.1 How would you rate your physical appearance?

F9.1.2 Are you able to accept your bodily appearance?

F9.1.3 Do you feel inhibited by your looks?

F9.1.4 Is there any part of your appearance that makes you feel uncomfortable?

Self-report subjective

F9.2.1 How do you feel about how you look?

F9.2.2 Do you like how you look?

F9.2.3 How satisfied are you with the way your body looks?

F9.2.4 How much do you worry about how you look?

Facet 10: Negative Feelings*Perceived objective*

- F10.1.1 How much are you affected by negative feelings (e.g., anger, sadness, depression, anxiety)?
- F10.1.2 How often do you have negative feelings, such as blue mood, despair, anxiety, depression?
- F10.1.3 How worried do you feel?
- F10.1.4 How depressed are you?
- F10.1.5 How often do you feel sad?
- F10.1.6 Do you feel hopeless?

Self-report subjective

- F10.2.1 To what extent do any negative feelings impair your life?
- F10.2.2 How much to any feelings of sadness or depression interfere with your everyday functioning?
- F10.2.3 How much to any feelings of depression bother you?
- F10.2.4 How much to any feelings of anxiety bother you in your everyday life?

DOMAIN III: LEVEL OF INDEPENDENCE**Facet 11: Mobility***Perceived objective*

- F11.1.1 How well are you able to get around?
- F11.1.2 Are you able to move freely without difficulty?
- F11.1.3 How much difficulty do you have getting around by yourself?
- F11.1.4 How much is your mobility limited?

Self-report subjective

- F11.2.1 How satisfied are you with your ability to move around?
- F11.2.2 How much do any difficulties in mobility bother you?
- F11.2.3 To what extent do any difficulties in movement affect your way of life?

Facet 12: Activities of Daily Living*Perceived objective*

- F12.1.1 To what extent are you able to carry out your daily activities?
- F12.1.2 How well are you able to take care of yourself in your everyday life?
- F12.1.3 To what extent do you have difficulty in performing your routine activities?

Self-report subjective

- F12.2.1 How satisfied are you with your ability to do normal, everyday things, for example, washing, dressing, and preparing food?
- F12.2.2 How satisfied are you with your ability to manage in your daily life?
- F12.2.3 How satisfied are you with your ability to perform your daily living activities?
- F12.2.4 How much are you bothered by any limitations in performing everyday living activities?

Facet 13: Dependence on medication or treatments*Perceived objective*

- F13.1.1 How dependent are you on medications?
- F13.1.2 How much are you dependent on medical treatments?
- F13.1.3 How much do you need any medication to function in your daily life?
- F13.1.4 How much do you need any medical treatment to function in your daily life?

Self-report subjective

- F13.2.1 To what extent has using medicines improved your quality of life?
- F13.2.2 To what extent does your quality of life depend on the use of medical substances or medical aids?
- F13.2.3 To what extent do you feel concerned about the amount of medicines you take?

Facet 14: Dependence on nonmedicinal substances (e.g., alcohol, tobacco, drugs ...)*Perceived objective*

- F14.1.1 Do you need to take something such as alcohol, tobacco, or drugs to feel better?
- F14.1.2 Is there anything, other than prescribed medication, that you must take to make your life tolerable?
- F14.1.3 To what extent do you need a nonmedicinal substance to feel good (e.g., alcohol, tobacco, drugs)?
- F14.1.4 To what extent are you dependent on addictive substances?

Self-report subjective

- F14.2.1 How much does your use of alcohol, tobacco, or drugs improve your ability to handle day-to-day life?
- F14.2.2 How worried are you by your use of drugs such as alcohol or tobacco?
- F14.2.3 To what extent are you worried about any dependence on nonmedicinal substances?

Facet 15: Communication Capacity*Perceived objective*

- F15.1.1 How well are you able to communicate with others?
- F15.1.2 How easy is it for you to communicate with other people?
- F15.1.3 How well can you convey your thoughts to others?
- F15.1.4 Do you have trouble making yourself understood?
- F15.1.5 How well are you able to understand other people?

Self-report subjective

- F15.2.1 How satisfied are you with your ability to understand and respond to others appropriately?
- F15.2.2 How satisfied are you with your ability to communicate with others?
- F15.2.3 How satisfied are you with how you communicate?
- F15.2.4 How satisfied are you with your ability to get your thoughts or ideas across to others?
- F15.2.5 How satisfied are you with your ability to understand others?

Facet 16: Working Capacity*Perceived objective*

- F16.1.1 Are you able to work?
- F16.1.2 Do you feel able to carry out your duties?
- F16.1.3 How would you rate your ability to work?
- F16.1.4 How limited is your ability to work?

Self-report subjective

- F16.2.1 How satisfied are you with your capacity for work?

DOMAIN IV: SOCIAL RELATIONSHIPS**Facet 17: Personal Relationships***Perceived objective*

- F17.1.1 To what extent do you have good relationships with other people?
- F17.1.2 How are the personal relationships in your life?
- F17.1.3 How alone do you feel in your life?
- F17.1.4 Are you able to develop close relationships with others?

Self-report subjective

- F17.2.1 Do you feel happy about your relationship with your family members?
- F17.2.2 How happy are you in your personal relationships (friendships, marriage)?
- F17.2.3 How satisfied are you with your personal relationships?
- F17.2.4 How satisfied are you with your intimate relationship(s)?

Facet 18: Practical Social Support*Perceived objective*

- F18.1.1 To what extent can you count on your family when you need them?
- F18.1.2 Do you get the kind of support from others that you need?
- F18.1.3 How much of the time do you feel that you can get the support of those around you in difficult times?
- F18.1.4 How much support do you get from your family?
- F18.1.5 To what extent can you count on your friends when you need them?
- F18.1.6 How much support do you get from your friends?

Self-report subjective

- F18.2.1 How happy are you with the support your family provides?
- F18.2.2 How satisfied are you with the support you get from your family?
- F18.2.3 How satisfied are you with the support provided by those around you when needed?
- F18.2.4 How satisfied are you with your friends' support?
- F18.2.5 How satisfied are you with the support you get from your friends?

Facet 19: Activities as Provider/Supporter*Perceived objective*

- F19.1.1 How much do you feel you have to carry all the family's problems on your shoulders?
- F19.1.2 How would you rate your ability to provide for or support others?

Self-report subjective

- F19.2.1 How satisfied are you with your ability to provide for or support others?
- F19.2.2 How satisfied are you with the help you provide others?
- F19.2.3 How much do you get satisfaction from caring for others?
- F19.2.4 How much does any taking care of another person interfere with your everyday life?
- F19.2.5 How much of a burden do you find caring for others?

DOMAIN V: ENVIRONMENT

Facet 20: Physical Safety and Security

Perceived objective

- F20.1.1 To what degree do you feel safe where you live?
- F20.1.2 How safe do you feel in your daily life?
- F20.1.3 Do you feel you are living in a safe and secure environment?
- F20.1.4 How would you rate your level of freedom?

Self-report subjective

- F20.2.1 Does concern about the safety and security of your surroundings affect the way you live?
- F20.2.2 How much do you worry about your safety and security?
- F20.2.3 How satisfied are you with your physical safety and security?
- F20.2.4 How satisfied are you with your level of freedom?

Facet 21: Home Environment

Perceived objective

- F21.1.1 How comfortable is the place where you live?
- F21.1.2 To what degree does the quality of your home meet your needs?
- F21.1.3 How satisfactory are your living conditions?

Self-report subjective

- F21.2.1 How satisfied are you with your home?
- F21.2.2 How satisfied are you with the conditions of your living place?
- F21.2.3 How satisfied are you with the comfort of your living conditions?
- F21.2.4 How much do you like it where you live?

Facet 22: Work Satisfaction

Perceived objective

- F22.1.1 How much do you like your work?
- F22.1.2 How much do you value working?
- F22.1.3 How good are the conditions in which you work?
- F22.1.4 How would you rate your relations with people in your work environment?
- F22.1.5 How well does your work suit you?

Self-report subjective

- F22.2.1 How satisfying is your work?
- F22.2.2 How much satisfaction do you get from your work?
- F22.2.3 How satisfied are you with your work?
- F22.2.4 How satisfied are you with your working conditions?

Facet 23: Financial Resources

Perceived objective

- F23.1.1 Have you enough money to meet your needs?
- F23.1.2 Do you get enough money to meet your needs?
- F23.1.3 How well are you able to meet your needs with the money you have?
- F23.1.4 How well can you manage on your money?
- F23.1.5 Do you have financial difficulties?

Self-report subjective

- F23.2.1 How satisfied are you with the way the money you have takes care of your needs?
- F23.2.2 How satisfied are you with the amount of money you have?
- F23.2.3 How satisfied are you with your financial situation?
- F23.2.4 How much do you worry about money?

Facet 24: Health and Social Care: Availability and Quality

Perceived objective

- F24.1.1 How easily are you able to get good medical care?
- F24.1.2 How difficult is it for you to access health services when you need them?
- F24.1.3 How would you rate the health care you get?
- F24.1.4 How difficult is it for you to access social services when you need them?
- F24.1.5 How would you rate the quality of social services available to you?

Self-report subjective

- F24.2.1 How satisfied are you with your access to health services?
- F24.2.2 How satisfied are you with the quality of the health services available to you?
- F24.2.3 How satisfied are you with the health care you obtain?
- F24.2.4 How satisfied are you with the availability of social services?
- F24.2.5 How satisfied are you with the social care services?

Facet 25: Opportunities for Acquiring New Information and Skills*Perceived objective*

- F25.1.1 How available to you is the information that you need in your day-to-day life?
- F25.1.2 To what extent do you have opportunities for acquiring the information that you feel you need?
- F25.1.3 How well informed are you about what is happening around you?

Self-report subjective

- F25.2.1 How satisfied are you with your opportunities for acquiring new skills?
- F25.2.2 How satisfied are you with your opportunities to learn new information?
- F25.2.3 How satisfied are you with your opportunities for learning?

Facet 26: Participation in and Opportunities for Recreation/Leisure Activities*Perceived objective*

- F26.1.1 Do you have enough leisure time?
- F26.1.2 To what extent do you have the opportunity for leisure activities?
- F26.1.3 How much are you able to relax and enjoy yourself?

Self-report subjective

- F26.2.1 How satisfying are your leisure time activities?
- F26.2.2 How much do you enjoy your free time?
- F26.2.3 How satisfied are you with the way you spend your spare time?

Facet 27: Physical Environment*Perceived objective*

- F27.1.1 How would you rate your physical environment (e.g., in terms of pollution, climate, noise, attractiveness)?
- F27.1.2 How healthy is your physical environment?
- F27.1.3 How polluted is the environment where you live?
- F27.1.4 How noisy is the area in which you live?

Self-report subjective

- F27.2.1 How satisfied are you with your physical environment (e.g., in terms of pollution, climate, noise, attractiveness)?
- F27.2.2 How concerned are you with the pollution in the area you live in?
- F27.2.3 How satisfied are you with the climate of the place where you live?
- F27.2.4 How concerned are you with the noise in the area you live in?
- F27.2.5 How satisfied are you with the water facilities where you live (availability and quality of water for drinking, cooking, and bathing)?

Facet 28: Transport*Perceived objective*

- F28.1.1 How available is transport when you require it?
- F28.1.2 To what extent do you have deqaure means of transport?
- F28.1.3 How easily can you get around using the transport available to you?
- F28.1.4 To what extent do you have problems with transport?

Self-report subjective

- F28.2.1 How satisfied are you with the means of travel available to you?
- F28.2.2 How satisfied are you with your transport?
- F28.2.3 How much do difficulties with transport restrict your life?

DOMAIN VI: SPIRITUALITY/RELIGION/PERSONAL BELIEFS*Perceived objective*

- F29.1.1 Do your personal beliefs give meaning to your life?
- F29.1.2 How much does religion have a positive influence on your life?
- F29.1.3 To what extent do you feel your life to be meaningful?
- F29.1.4 To what extent does spirituality give meaning to your life?

Self-report subjective

- F29.2.1 How satisfied are you with your spiritual life?
- F29.2.2 To what extent do your personal beliefs give you the strength to face difficulties?
- F29.2.3 To what extent do your personal beliefs help you to understand difficulties in life?
- F29.2.4 How satisfied are you with the purpose and meaning in your life?

Instructies

Wij vragen u om in deze vragenlijst aan te geven wat u vindt van uw kwaliteit van leven, gezondheid en andere levensgebieden. Beantwoord alstublieft alle vragen. Als u onzeker bent over het antwoord dat u wilt geven op een vraag, kies dan het antwoord dat het meest toepasselijk lijkt. Dit kan vaak uw eerste reactie zijn.

Houd uw normen, hoop, genoegens en zorgen in gedachten. We vragen u te denken aan uw leven in de **afgelopen twee weken**.

Bijvoorbeeld, met betrekking tot de laatste twee weken, zou een vraag kunnen luiden:

Hoeveel zorgen maakt u zich over uw gezondheid?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

U moet het cijfer omcirkelen dat het beste past bij hoe vaak u zich in de afgelopen twee weken zorgen heeft gemaakt over uw gezondheid. Dus u moet het cijfer 4 omcirkelen, als u zich veel ("Hevig") zorgen heeft gemaakt over uw gezondheid, of het cijfer 1 "Helemaal Niet" als u zich helemaal geen zorgen heeft gemaakt over uw gezondheid. Leest u alstublieft elke vraag, ga uw gevoelens na en omcirkel voor elke vraag het cijfer van de schaal dat het beste bij u past.

Dank u voor uw hulp.

In de volgende vragen wordt gevraagd in welke mate (hoeveel) u in de afgelopen twee weken bepaalde dingen hebt ervaren, bijvoorbeeld positieve gevoelens zoals geluk en tevredenheid. Als u deze in een extreme hoeveelheid hebt ervaren, omcirkel dan het cijfer 5 onder "Een Extreme Hoeveelheid". Als u dergelijke zaken helemaal niet hebt ervaren, omcirkel dan het cijfer 1 onder "Helemaal Niet". De tussenliggende cijfers kunt u gebruiken om aan te geven dat het ergens tussen "Helemaal Niet" en "Helemaal" in ligt. Vragen verwijzen naar de afgelopen twee weken.

F1.2 Maakt u zich zorgen over uw pijn of ongemak?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F1.3 Hoe moeilijk is het voor u om om te gaan met pijn of ongemak?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F1.4 In welke mate vindt u dat pijn u afhoudt van wat u moet doen?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F2.2 Hoe gemakkelijk raakt u vermoeid?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F3.2 In welke mate hebt u problemen met slapen?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F3.4 Hoeveel zorgen maakt u zich over enigerlei problemen met slapen?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F4.1 Hoeveel geniet u van het leven?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F4.3 Hoe positief ziet u uw toekomst?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F4.4 Hoezeer ervaart u positieve gevoelens in uw leven?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F5.3 Hoe goed kunt u zich concentreren?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F6.1 Heeft u waardering voor uzelf?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F6.2 Hoeveel vertrouwen hebt u in uzelf?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F7.2 Voelt u zich geremd door uw uiterlijk?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F7.3 Is er iets in uw uiterlijk op grond waarvan u zich ongemakkelijk voelt?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F8.2 Hoe bezorgd voelt u zich?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F8.3 Hoezeer verstoren gevoelens van droefheid of depressie uw alledaagse functioneren?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F8.4 Hoeveel last hebt u van depressieve gevoelens?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F10.2 In welke mate hebt u moeilijkheden met het doen van uw routine-activiteiten?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F10.4 Hoeveel hinder ondervindt u van allerlei beperkingen in het doen van alledaagse levensactiviteiten?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F11.2 Hoeveel behoefte hebt u aan enigerlei medicatie om in uw dagelijkse leven te kunnen functioneren?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F11.3 Hoeveel behoefte hebt u aan medische behandeling om in uw dagelijkse leven te kunnen functioneren?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F11.4 In welke mate hangt uw kwaliteit van leven af van het gebruik van medicijnen of medische hulpmiddelen?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F13.1 Hoe alleen voelt u zich in uw leven?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F15.2 Hoe goed zijn uw seksuele behoeften vervuld?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F16.1 Hoe veilig voelt u zich in uw dagelijkse leven?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F16.2 Vindt u dat u in een veilige omgeving woont?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F16.3 Hoeveel zorgen maakt u zich over uw veiligheid?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F17.4 Hoe erg bevalt het u waar u woont?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F18.2 Hebt u financiële moeilijkheden?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F18.4 Hoeveel zorgen maakt u zich over geld?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F19.1 Hoe gemakkelijk kunt u goede medische zorg krijgen?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F21.3 Hoeveel geniet u van uw vrije tijd?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F22.1 Hoe gezond is uw omgeving?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F22.2 Hoeveel zorgen heeft u over het lawaai in het gebied waarin u woont?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F23.2 In welke mate hebt u problemen met vervoer?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F23.4 Hoe erg beperken moeilijkheden met vervoer uw leven?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F2.4 Heeft u last van vermoeidheid?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F15.4 Heeft u last van moeilijkheden in uw sexleven?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

In de volgende vragen wordt gevraagd naar **de mate waarin** u bepaalde dingen ervaart of in staat was te doen in de afgelopen twee weken, bijvoorbeeld alledaagse activiteiten zoals wassen, aankleden of eten. Als u in staat bent geweest deze dingen helemaal te doen, omcirkel dan het cijfer 5 onder "Helemaal". Als u niet in staat bent geweest om al deze dingen te doen, omcirkel dan het cijfer 1 onder "Helemaal niet". De tussenliggende cijfers kunt u gebruiken om aan te geven dat het ergens tussen "Helemaal Niet" en "Helemaal" in ligt. Vragen verwijzen naar de afgelopen twee weken.

F2.1 Hebt u genoeg energie voor het leven van alledag?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F7.1 Kunt u uw lichamelijke uiterlijk accepteren?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F10.1 In welke mate kunt u uw dagelijkse dingen doen?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F11.1 Hoe afhankelijk bent u van medicaties?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F14.1 Krijgt u het soort steun dat u nodig hebt, van anderen?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F14.2 In welke mate kunt u rekenen op uw vrienden als u ze nodig hebt?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F17.1 Hoe comfortabel is de plaats waar u woont?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F17.2 In welke mate komt de kwaliteit van uw huis tegemoet aan uw behoeften?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F18.1 Hebt u genoeg geld om in uw behoeften te voorzien?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F20.1 Hoe beschikbaar voor u is de informatie, die u nodig hebt in uw dagelijkse leven?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F20.2 In welke mate hebt u mogelijkheden om de informatie te verkrijgen waarvan u vindt dat u die nodig heeft?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F21.1 Hebt u mogelijkheden tot recreatie?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F21.2 Hoe goed kunt u zich ontspannen en uzelf vermaken?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F23.1 In welke mate hebt u geschikte middelen van vervoer?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

In de volgende vragen wordt gevraagd naar hoe **tevreden of ontevreden** u in de afgelopen twee weken bent geweest met de verschillende aspecten van uw leven; bijvoorbeeld, uw familieleven of uw vermogen om met degenen om u heen te communiceren. Beslis hoe tevreden of ontevreden u bent met elk aspect van uw leven en omcirkel het cijfer dat het beste past bij wat u hierover vindt.

G2 Hoe tevreden bent u met de kwaliteit van uw leven?

Erg Onte tevreden	Onte tevreden	Tevreden noch Onte tevreden	Content	Erg Tevreden
1	2	3	4	5

G3 Hoe tevreden bent u met uw leven in het algemeen?

Erg Onte tevreden	Onte tevreden	Tevreden noch Onte tevreden	Content	Erg Tevreden
1	2	3	4	5

G4 Hoe tevreden bent u met uw gezondheid?

Erg Onte tevreden	Onte tevreden	Tevreden noch Onte tevreden	Content	Erg Tevreden
1	2	3	4	5

F2.3 Hoe tevreden bent u met de energie die u heeft?

Erg Onte tevreden	Onte tevreden	Tevreden noch Onte tevreden	Content	Erg Tevreden
1	2	3	4	5

F3.3 Hoe tevreden bent u met uw slaap?

Erg Onte tevreden	Onte tevreden	Tevreden noch Onte tevreden	Content	Erg Tevreden
1	2	3	4	5

F5.2 Hoe tevreden bent u met uw vermogen om nieuwe informatie te leren?

Erg Onte tevreden	Onte tevreden	Tevreden noch Onte tevreden	Content	Erg Tevreden
1	2	3	4	5

F5.4 Hoe tevreden bent u met uw vermogen om beslissingen te nemen?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F6.3 Bent u tevreden met uzelf?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F6.4 Hoe tevreden bent u met uw bekwaamheden?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F7.4 Hoe tevreden bent u met uw uiterlijk?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F10.3 Bent u tevreden met uw vermogen om alledaagse activiteiten te verrichten?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F13.3 Hoe tevreden bent u met uw persoonlijke relaties?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F15.3 In welke mate bent u tevreden met uw seksuele leven?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F14.3 Hoe tevreden bent u met de steun die u krijgt van uw familie?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F14.4 Hoe tevreden bent u met de steun die u krijgt van uw vrienden?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F13.4 Hoe tevreden bent u met uw vermogen om voor anderen te zorgen of hen steun te geven?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F16.4 Hoe tevreden bent u met uw lichamelijke veiligheid?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F17.3 Bent u tevreden met uw leefomstandigheden?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F18.3 Hoe tevreden bent u met uw financiële situatie?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F19.3 Hoe tevreden bent u met uw toegang tot gezondheidsdiensten?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F19.4 Hoe tevreden bent u met de sociale diensten?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F20.3 Bent u tevreden met uw mogelijkheden om nieuwe vaardigheden te verwerven?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F20.4 Bent u tevreden met uw mogelijkheden om nieuwe informatie te verwerven?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F21.4 Hoe tevreden bent u met de manier waarop u uw vrije tijd doorbrengt?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F22.3 Hoe tevreden bent u met uw natuurlijke omgeving (bijv. vervuiling, klimaat, lawaai, aantrekkelijkheid)?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F22.4 Hoe tevreden bent u met het klimaat in het gebied waarin u woont?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F23.3 Hoe tevreden bent u met uw vervoer?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F13.2 Voelt u zich gelukkig met uw relatie met uw familieleden?

Erg Ongelukkig	Tamelijk Ongelukkig	Gelukkig noch Ongelukkig	Tamelijk Gelukkig	Erg Gelukkig
1	2	3	4	5

G1 Hoe zou u uw kwaliteit van leven inschatten?

Erg Slecht	Tamelijk Slecht	Goed noch Slecht	Tamelijk Goed	Erg Goed
1	2	3	4	5

F15.1 Hoe zou u uw sexleven beoordelen?

Erg Slecht	Tamelijk Slecht	Goed noch Slecht	Tamelijk Goed	Erg Goed
1	2	3	4	5

F3.1 Hoe goed slaapt u?

Erg Slecht	Tamelijk Slecht	Goed noch Slecht	Tamelijk Goed	Erg Goed
1	2	3	4	5

F19.2 Wat vindt u van de kwaliteit van de sociale diensten die u ter beschikking staan?

Erg Slecht	Tamelijk Slecht	Goed noch Slecht	Tamelijk Goed	Erg Goed
1	2	3	4	5

F5.1 Hoe zou u uw geheugen beoordelen?

Erg Slecht	Tamelijk Slecht	Goed noch Slecht	Tamelijk Goed	Erg Goed
1	2	3	4	5

De volgende vragen verwijzen naar **hoe vaak** u bepaalde dingen hebt gevoeld of ervaren, bijvoorbeeld de steun van uw familie of vrienden of negatieve ervaringen, zoals zich onveilig voelen. Als u deze dingen helemaal niet heeft ervaren in de afgelopen twee weken, omcirkel dan het cijfer 1 onder "Nooit". Als u deze dingen wel heeft ervaren, beslis dan hoe vaak en omcirkel het toepasselijke cijfer. Dus, bijvoorbeeld, als u de afgelopen twee weken de hele tijd pijn hebt ervaren, omcirkel dan het cijfer 5 onder "Altijd". Vragen verwijzen naar de afgelopen twee weken.

F1.1 Hoe vaak heeft u een gevoel van pijn gehad?

Nooit	Zelden	Zo nu en dan	Redelijk Vaak	Altijd
1	2	3	4	5

F4.2 Voelt u zich over het geheel genomen tevreden?

Nooit	Zelden	Zo nu en dan	Redelijk Vaak	Altijd
1	2	3	4	5

F8.1 Hoe vaak heeft u negatieve gevoelens, zoals een sombere stemming, wanhoop, angst, depressie?

Nooit	Zelden	Zo nu en dan	Redelijk Vaak	Altijd
1	2	3	4	5

De volgende vragen verwijzen naar alle soorten "**werk**" die u verricht. Werk betekent hier elke redelijk omvangrijke activiteit die u verricht. Dit omvat vrijwilligerswerk, voltijds studeren, zorgen voor het huis, zorgen voor kinderen, betaald werk, onbetaald werk. Dus werk, zoals het hier wordt gebruikt, slaat op die activiteiten waarvan u vindt dat ze een groot deel van uw tijd en energie innemen. Vragen verwijzen naar de afgelopen twee weken.

F12.1 Bent u in staat om uw werk te verrichten?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F12.2 Voelt u zich in staat om aan uw dagelijkse verplichtingen te voldoen?

Helemaal Niet	Bijna Niet	Gemiddeld	Nogal	Helemaal
1	2	3	4	5

F12.4 Bent u tevreden met uw werkvermogen?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F12.3 Hoe zou u uw werkvermogen inschatten?

Erg Slecht	Tamelijk Slecht	Goed noch Slecht	Tamelijk Goed	Erg Goed
1	2	3	4	5

In de volgende vragen wordt gevraagd naar **hoe goed u in staat was om zich te verplaatsen** in de afgelopen twee weken. Dit verwijst naar uw lichamelijk vermogen om uw lichaam te bewegen op zo'n manier dat het u in staat stelt rond te lopen en de dingen te doen die u zou willen doen, alsook de dingen die u moet doen.

F9.3 Hoeveel last hebt u van problemen bij het zich verplaatsen?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F9.4 In welke mate beïnvloeden moeilijkheden met beweging uw manier van leven?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F9.2 Hoe tevreden bent u met de manier waarop u in staat bent zich te verplaatsen?

Erg Ontevreden	Ontevreden	Tevreden noch Ontevreden	Content	Erg Tevreden
1	2	3	4	5

F9.1 Hoe goed kunt u zich verplaatsen?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

De volgende paar vragen gaan over uw **persoonlijke overtuigingen** en hoe deze uw leven beïnvloeden. Deze vragen verwijzen naar geloof, spiritualiteit of enigerlei andere overtuigingen die u zou kunnen hebben. Opnieuw verwijzen deze vragen naar de laatste twee weken.

F24.1 Geven uw persoonlijke overtuigingen betekenis aan uw leven?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F24.3 In welke mate geven uw persoonlijke overtuigingen u de kracht om moeilijkheden aan te kunnen?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F24.4 In welke mate helpt uw persoonlijke geloof u om moeilijkheden in het leven te begrijpen?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

F24.2 In welke mate voelt u dat uw leven betekenisvol is?

Helemaal Niet	Weinig	Middelmatig	Hevig	Een Extreme Hoeveelheid
1	2	3	4	5

APPENDIX XII Social support scales

Practical Support

Do you get practical support from your children?

Do you get practical support from your partner?

Do you get practical support from your family members?

Do you get practical support from your friends who do not suffer from CFS?

Do you get practical support from your fellow CFS sufferers?

Emotional Support

Do you get emotional support from your children?

Do you get emotional support from your partner?

Do you get emotional support from your family members?

Do you get emotional support from your friends who do not suffer from CFS?

Do you get emotional support from your fellow CFS sufferers?

Understanding

Do you get understanding from your children?

Do you get understanding from your partner?

Do you get understanding from your family members?

Do you get understanding from your friends who do not suffer from CFS?

*Emotional Well-Being scale***Satisfaction**

These are the best years of my life.
I feel that I have a number of good qualities.
I take a positive attitude toward myself.
As I look back on my life, I am fairly well satisfied.
I have gotten pretty much what I expected out of life.
I like everybody.
Recently, I feel like things are going my way.

Activity

I have trouble of thinking what to say in groups.
Recently, I felt proud about having accomplished something.
I sometimes become confused in conversation.
Most days I have plenty to do.
I have made plans for what I am going to do next month.

Neighboring scale

How often do you borrow or exchange things with your neighbors?
How often do you visit with your neighbors?
Within the past year, how often have people in this neighborhood helped you or you helped them with small tasks such as repair work or grocery shopping?
If an emergency arose in your home such as an accident requiring assistance of adults, could you call on your neighbors for help?
Do you feel you have a lot in common with your neighbors?
In general, how friendly is your neighborhood?

*Residential Satisfaction***Safety**

To what extent is crime a problem in your neighborhood?
How safe do you feel in your house/apartment during the daytime?
How safe do you feel in your house/apartment at night?

Physical Condition

How well are the houses in your neighborhood kept up?
To what extent is vacant buildings a problem in your neighborhood?
To what extent is run-down buildings a problem in your neighborhood?
To what extent is litter and garbage a problem in your neighborhood?
To what extent is street maintenance a problem in your neighborhood?

Proximity

How convenient is this neighborhood for shopping and getting the things you need?
Is your house/apartment within 4 blocks (or a 10 minute slow walk) of a grocery store or supermarket?
How convenient is your location of your home for visiting with friends?
How convenient is your location for getting health care?
How convenient is your location for attending the church/synagogue of your choice?
How convenient is your location to obtaining public transportation?

General Rating of Home Environment and Satisfaction with the House

All things considered, how would you rate this neighborhood as a place to live?
All things considered, how satisfied are you with your dwelling unit?

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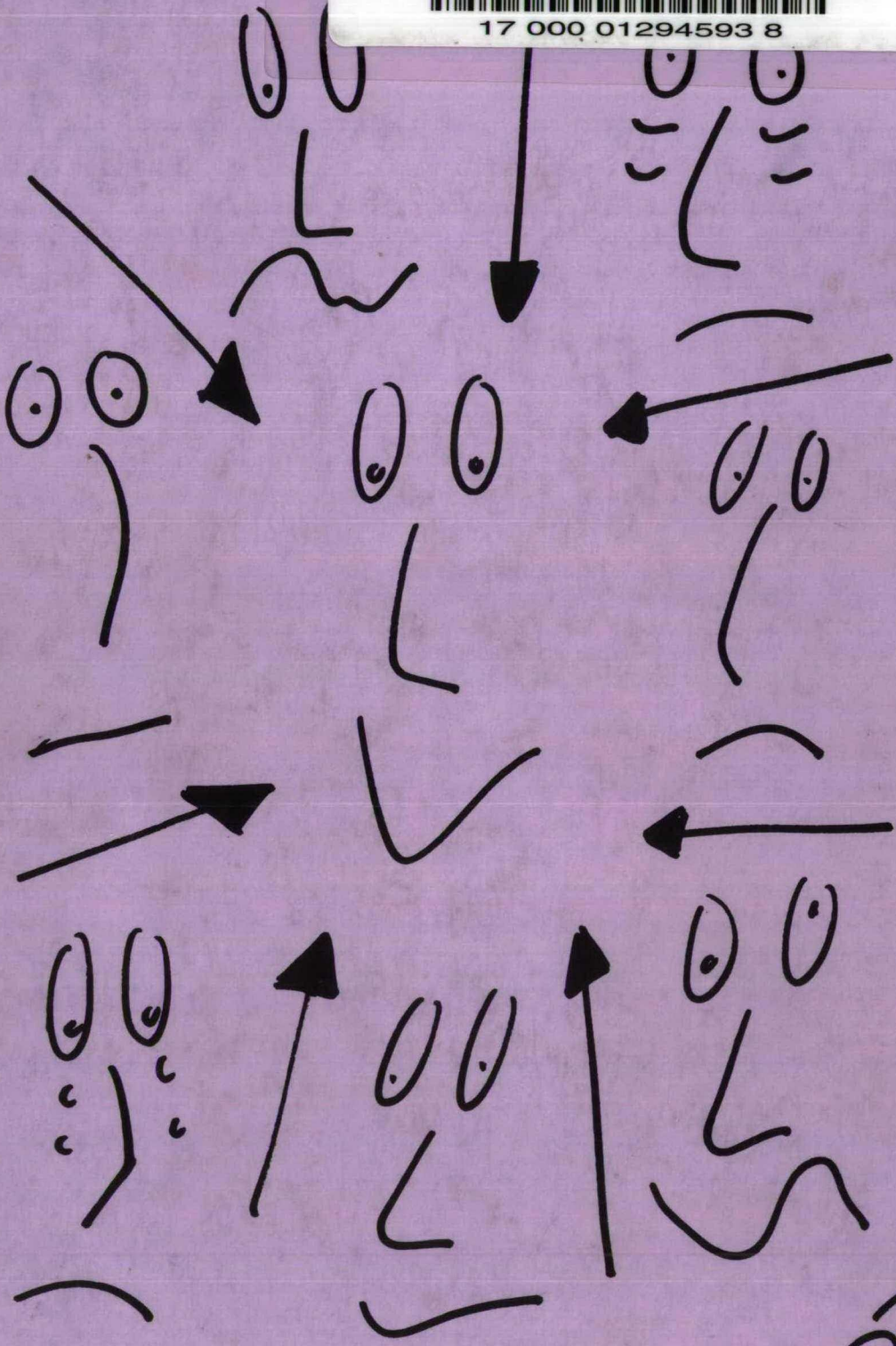
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