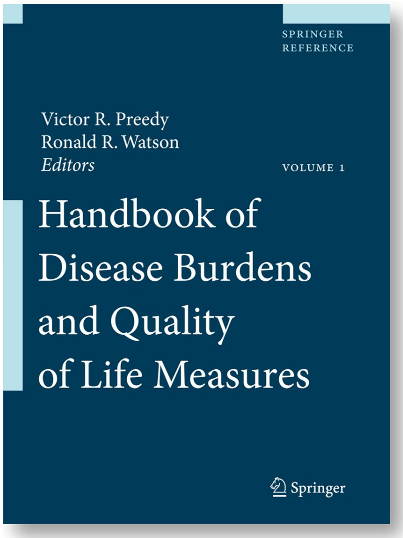

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Editors

VOLUME 1

Handbook of
Disease Burdens
and Quality
of Life Measures

Springer

2010, LX, 4448 p. In 6 volumes, not available separately.

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Handbook of Disease Burdens and Quality of Life Measures

- The first comprehensive book to address new methods of assessment and analyze new quality of life findings on an international scale
- Describes and assesses quantitative measures of quality of life, life expectancy, and the financial costs of illness and treatment
- An important resource for interpreting the many instruments used to measure quality of life
- Includes an extensive glossary, summary points, figures and tables that enhance the text or stand alone

The impact of illness on individual lives and society at large was once considered too vast to gauge. More recently, quantitative measures of quality of life, life expectancy, and the financial costs of illness and treatment are showing not only how this impact can be calculated but also how the results can be used to further research and improve public health. The Handbook of Disease Burdens and Quality of Life Measures is the first comprehensive reference to these instruments and their findings on an international scale.

The Handbook features in-depth reviews of disability-adjusted life years (DALYs), quality-adjusted life years (QALYs), quality of life and financial measures for over 120 diseases and conditions. Its editors have organized this critical information for maximum access and ease of use, with abstracts, definitions of key terms, summary points, and dozens of figures and tables that can enhance the text or stand alone. Readers may access data by country, region, or population, or by disease entity, e.g.:

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Viral, bacterial, microbial, parasitic, and other infectious diseases, including HIV/AIDS, tuberculosis, encephalitis, and dengue fever, plus vaccination issues.

Cancer, including breast, prostate, cervical, colorectal, and pediatric.

Psychosocial, psychiatric, sensory, and addictive (drugs, alcohol, tobacco) disorders.

Topics ranging from toxic exposure (injection contamination, occupational hazards, environmental pollutants), to special populations (children, the elderly in China, the city of Los Angeles), to commonly-occurring conditions (rheumatoid arthritis, menopause, macular degeneration).

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Part 3

3 Quality of Life Measures and Indices

3.1 General Aspects, Pathologies and Metabolic Disorders

102 Quality of Life-Related Concepts: Theoretical and Practical Issues

A. A. J. Wismeijer · A. J. J. M. Vingerhoets · J. De Vries

Abstract: Quality of Life (QOL) is a complex and multidimensional concept, which is related to a host of health concepts. In addition, there are several other concepts which seem to be related to quality of life. The focus of this chapter is to present an overview of, and introduction into QOL-related concepts, and to discuss how these concepts are measured and used in clinical practice. This concerns the following constructs: health status, illness related stressors, illness intrusiveness, impact of disease and suffering.

List of Abbreviations: *HS,* health status; *QOL,* quality of life; *WHO,* world health organization; *WHOQOL,* World Health Organization Quality of Life Questionnaire

1 Introduction

Quality of life (QOL) is an increasingly important theme both in scientific research and patient care. This increasing popularity can be explained by the broad recognition that QOL is a highly relevant outcome measure in medical treatment, forming an important addition to the traditional biomedical endpoints such as limitations in the functioning of organs, senses, or limbs or mortality (De Vries, 2001). The fact that such biomedical parameters are often only weakly associated with the subjective well-being of the patient emphasizes its additional value. QOL refers to (dis)satisfaction with various aspects of life.

The WHOQOL group (1994, 1995a, 1998a) has defined QOL as someone's perception of his/her position in life in relation to his/her goals, expectations, standards, values and cares. Two aspects of this definition are particularly important. First, it shows that QOL is a subjective concept that refers to positive as well as negative aspects of life, and second, QOL appears to be a broad and multidimensional concept. Health care professionals thus should pay special attention to not only the influence of the disease or handicap on the everyday functioning of their patients (= health status (HS)), but also to their patients' satisfaction with their physical, psychological, and social functioning (= QOL) (De Vries, 2001; De Vries and Drent, 2007).

The link between QOL and HS is clear, but there are also other concepts which very likely are associated with QOL, but which nevertheless concern distinct constructs. What these concepts have in common with QOL is that they relate to the impact of disease: To what extent is the daily life of a patient affected by his or her disease and what are the consequences for the patient? Below we will discuss some of these concepts.

2 Health Status

Health status (HS) is a first related concept, with notable and distinctive characteristics. The definitions of the QOL and HS concepts stress that both are multidimensional. In line with the definition of health by the WHO (1958), QOL studies and questionnaires focus on the physical, mental and social domain. These domains usually include a number of aspects. For example, the physical domain includes pain; the mental domain includes cognitive function and self-image, whereas social support belongs to the social domain. In addition, particularly in clinical trials the focus is often on illness and treatment-related symptoms. The multidimensionality of both concepts is important because the diversity of experiences can not be captured with a questionnaire that assesses only one dimension, for example, the physical dimension (Fitzpatrick et al., 1992). The fact that a total score can be computed for a number of HS questionnaires is not compatible with the proposed multidimensionality. Such a total score only contains very limited information and is not easily interpretable: a given total score on a multidimensional questionnaire can be the result of the sum of very different subscores (De Vries and Drent, 2007). For example, one patient may have problems mainly at the social level; another suffers mainly from mental problems, whereas the third patient has predominantly physical limitations. Nevertheless, their total scores may be similar.

Unfortunately, the concepts HS (also known as health-QOL) and QOL are often used interchangeably, as synonyms, which may easily induce confusion. Many studies suggest in their titles that they assess QOL, while actually HS has been measured. More precisely, for HS, the main issue is to what extent one's functioning is limited. For example, can someone still walk, dress him/herself, go shopping, or maintain social contacts. QOL, in contrast, focuses on how (dis)satisfied the individual is with what s/he is still able to do.

Research has clearly demonstrated that physical limitations or malfunctioning not always imply a poor QOL. Individual expectations about health, ambitions that can no longer be achieved, the (in)ability to cope with restrictions, the tolerance for discomfort and self-efficacy regarding disease are important determinants of one's QOL. For instance, two people with similar limitations in functioning (HS) may evaluate their QOL very differently. A low score on HS can go along with a high score on a corresponding QOL domain and vice versa (De Vries, 2001; De Vries and Drent, 2006). Take as an example the impact of a problem with a knee for a middle-aged office manager and for a 22-year-old talented soccer player.

Another difference between the two concepts is that QOL addresses both positive and negative aspects of one's functioning. This is also reflected in the items included in QOL questionnaires: not only do they address one's limitations and how one feels about those limitations, but they also address what one still can do and to what extent one is satisfied. This is a contrast with HS questionnaires that mainly focus on the limitations of the respondent, which can easily lead to a negative response tendency.

It is often stated that HS questionnaires are in fact also a measure of QOL because they are completed by the patients themselves, and thus are subjective. However, there are two meanings of the word subjective in this context. First, it means that QOL and HS measures both are filled out by patients. However, the second meaning refers to the fact that patients report their own evaluation of their health status, which is a major difference with HS questionnaires. This distinction between HS and QOL is important because they can lead to different results and recommendations.

Two frequently applied health status questionnaires are the Sickness Impact Profile (SIP; Jacobs et al., 1990) and the Medical Outcomes Study Short Form – 36 (SF-36; Ware et al., 1993). From the Medical Outcomes Study several disease-specific HS questionnaires have been derived, such as for hypertension, diabetes, thyroid disease, etc (e.g., Brooks et al., 1982).

3 Other QOL-Related Concepts

In addition to HS, there are some more health psychology concepts that seem to be in some way associated to QOL and therefore deserve adequate attention. For example, the concept of illness-related stressors, the consequences of illness and disability for one's life goals ("illness intrusiveness"), the impact the disease has on several aspects of life, disease burden and suffering all seem to have some conceptual overlap with QOL. For all these concepts, assessment methods have recently become available. Below we will briefly introduce some of these concepts.

3.1 Illness-Related Stressors

The term stressor refers to a stimulus, situation, event or condition that has the potential to evoke stress reactions. Many of the stressors one is exposed to concern random events that just happen; its occurrence is not related to the functioning of the individual. Being confronted with them is merely a matter of bad luck, such as, for example, being at the wrong place at the wrong moment. However, stressors also may be rather closely associated to one's personality, functioning and health status (Vingerhoets et al., 1989). People create to a large extent, aware or unaware, their own environment by avoiding certain situations and actively searching for others. A simple illustration of this idea is that individuals will not be hospitalized and undergo painful medical procedures, unless they are suffering from a serious health problem. That is, the exposure to these stressors depends fully on one's health status (Prugh and Thompson, 1990; Schechter and Leigh, 1990). Also other stressors may be related to one's functioning and/or health status, such as the loss of one's job, having financial problems, loss of the capacity to engage in certain hobbies, being forced to move, etc. This is nicely demonstrated by Blokhorst et al. (2002), who found that whiplash patients, compared to healthy controls, obtained equal scores on the so-called person-independent stressors, but scored significantly higher on the person-dependent stressors of the Everyday Problems Checklist (EPCL; Vingerhoets and Van Tilburg, 1994). Interestingly, the patients rated the impact of both categories of stressors higher than the healthy controls, which may be interpreted as an indication that the patient group is more vulnerable to stress.

The EPCL contains 114 items representing everyday events that have the potential to provoke a variety of negative emotions, including fear, anger, disappointment, guilt, regret and embarrassment. It has adequate psychometric features and a unique characteristic concerns the above described two subscales with, respectively, person-dependent and person-independent items. These scales were based on the ratings of each item by behavioral scientists and clinicians how likely it is that the occurred event described by the item can be attributed to the person. As support for the validity of this distinction, it was found that individuals scoring high on neuroticism also especially score higher on person-dependent items. Example items of this checklist are shown in ➲ *Table 102-1*. Especially the patients' score on the person-dependent items may thus be interpreted as an indication of the impact of the disease.

A move into a nursery home or a hospitalization, in particular when it implies that one has to undergo painful medical procedures, is generally experienced as rather stressful. Some studies have specifically focused on the assessment of stressors in the medical context (e.g., Koenig et al., 1995). This research revealed that the interaction with health professionals and especially the lack of information stand out as sources of stress. In addition, the hospital environment (the noise, rigid routines, lack of privacy), worrying about the home situation, homesickness, being stigmatized and discriminated by health care providers or fellow patients, and the fear or losing one's independency and autonomy as well as loss of control are chief determinants of patient stress. Finally, as said before, painful procedures and interventions that may be a threat to one's physical or psychological integrity may contribute to the stress experienced by hospitalized patients. Specific questionnaires have been designed to evaluate

Table 102-1
Examples of items from the Everyday Problems Checklist (EPCL; Vingerhoets and van Tilburg, 1994)

Person-dependent items
1. Important possessions were lost
6. You wanted things you were not able to afford financially
78. You failed to accomplish tasks that you thought you were capable of doing
104. You could not be yourself
110. You unintentionally insulted someone
Person-independent items
8. Your sleep was disturbed
16. You were unemployed or temporarily laid off
62. People around you behaved irresponsibly
74. Your favorite team suffered defeat and/or humiliation
105. You witnessed a traffic accident or criminal offense

the impact of having to undergo stressful medical procedures. In addition, there is ample attention for parents and family members of children with serious health conditions that are hospitalized in intensive care units (Board and Ryan-Wenger, 2003; Spear et al., 2002). To summarize, having to live with a disease not only implies the experience of symptoms, but not exceptionally it has major consequences such as hospitalization, undergoing intensive medical treatments, as well as influence on work and relationships.

3.2 Illness Impact

Disease and disability can strongly interfere with one's life goals, and hence affect well-being. Future plans need to be drastically revised, because they can not be realized. Carefully planned careers are thwarted and dramatic adaptations are required. Some researchers focus especially on the relationship between the attainment of life goals and well-being (e.g., Schmuck and Sheldon, 2001). Their research reveals that a global distinction can be made between individuals whose main aim is to avoid negative situations, whereas for others the focus is more on seeking pleasure. Until now, little is known about the effects of disease on the well-being of these two groups of people.

Illness Intrusiveness is assessed with the Illness Intrusiveness Rating Scale (IIRS; Devins et al., 2001), consisting of 13 items. Implicit in this concept is that the disruption of lifestyles and activities attributable to constraints imposed by chronic disease and its treatment has a major impact on one's well-being. The respondents have to indicate to what extent their disease has an impact on 13 dimensions of their life, including relationships, work, trust in one's body, etc. However, this measure only asks for the extent of the impact; there is no specification whether the impact is considered as negative or positive. Generally, negative associations are reported with QOL, whereas there is a positive connection with depression (Schimmer et al., 2001). What we consider a major disadvantage of this instrument is that the respondent thus has no possibility to indicate that his/her health problem also may have a positive influence on one's life.

Inspired by the IIRS and being aware of the above limitation, we have recently developed the Perceived Disease Impact Scale (PDIS; Mols et al., 2007; van Gestel et al., 2007) which differs from the IIRS in two important aspects. First, we added eight items, resulting in a total of 21 items. *Table 102-2* shows some examples of the items. And, second, the respondents had to indicate whether they perceived the impact of their disease on the listed aspects of life as neutral, positive or negative. This proved to be very important because, in particular with long term cancer survivors, but also among women with fertility problems, it appeared that the effects of the disease were not just negative. That is, patients also indicated positive effects of their disease on several aspects of their life. While the effects of (breast) cancer are almost always negative in the immediate aftermath of diagnosis, years later these effects apparently are not only negative. Whereas approximately 30% of breast cancer survivors still experience specific complaints, there is also evidence that many long-term survivors experience a good quality of life 5 years or more after diagnosis. Some recent studies have provided evidence that cancer patients engage in what is referred to as "benefit finding." Well-known examples of these benefits are a greater appreciation of life and a change in life priorities. In addition, the literature also suggests that after cancer, patients may experience posttraumatic growth. Posttraumatic growth refers to the success with which individuals, coping with the aftermath of trauma, reconstruct or strengthen their perceptions of self, others, and the meaning of events (see *Figure 102-1*). Whereas benefit-finding may start immediately after diagnosis, research suggests that posttraumatic growth specifically develops first after a process of rumination and restructuring that occurs in the weeks, months, and even years following the trauma. A striking illustration of these processes is provided by multiple Tour de France-winner Lance Armstrong:

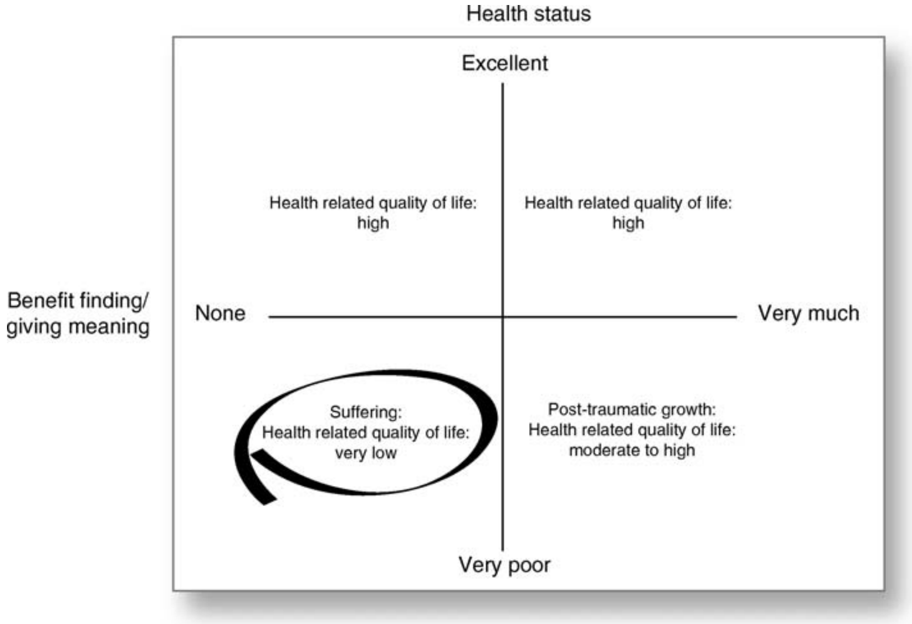
Table 102-2
Examples of items from the Perceived Disease Impact Scale (PDIS; Mols et al., 2007)

To what degree did your disease and/or the treatment affect your current:
1. Physical health
9. Financial situation
15. Personal development
17. Sense of involvement to what happens in the world
20. Confidence in your body

> "When I was 25, I got testicular cancer and nearly died," writes Armstrong in his 2001 memoir *It's Not About the Bike: My Journey Back to Life.* "I was given less than a 40% chance of surviving, and frankly, some of my doctors were just being kind when they gave me those odds." (. . .) "There are two Lance Armstrongs, pre-cancer and post. Everybody's favourite question is "How did cancer change you?" The real question is how didn't it change me? I left my house on October 2, 1996 as one person and came home another. . . . The truth is that cancer was the best thing that ever happened to me. I don't know why I got the illness, but it did wonders for me, and I wouldn't want to walk away from it. Why would I want to change, even for a day, the most important and shaping event of my life?"

Until now, (long-term) adaptation to (breast) cancer has been measured traditionally by means of questionnaires about well-being or (health-related) QOL. However, such measures

Figure 102-1
Schematic representation of a model with health complaints, suffering and posttraumatic growth



typically fail to offer any insight into *precisely* which specific domains of life are (no longer) positively or negatively affected. These measures also lack the capacity to assess the *positive* effects of cancer and/or its treatment on the different life-domains. For this reason, we decided to determine which life domains were *positively* or *negatively* affected in long-term breast cancer survivors. We also wanted to know which patient or tumor characteristic, in terms of age, stage and treatment, was associated with the least negative or most positive effects of cancer and its treatment on their lives. In *Table 102-3* we summarize the findings obtained in different patient groups. The results are striking in at least two ways. First, there is the remarkable correspondence among different groups of cancer patients/survivors. Second, compared to cancer survivors other patient groups apparently report far less positive effects of their disease.

However, what is most important, is that researchers and clinicians as well should be careful to infer conclusions about the impact of a disease. Prejudices may easily lead to wrong perceptions, implying that the patients do not receive the care and attention that they really need. An interesting example in this respect is hair loss in cancer patients after being treated with chemotherapy. Mulders et al. (2008) showed that oncology nurses and physicians underestimated the relevance of this side effect of chemotherapy. Using a specially designed so called psychophysical scaling method, these investigators compared the perceived impact of several cancer and cancer treatment related effects. Whereas there was a close correspondence between nurses and physicians, both groups grossly overestimated and underestimated various issues. For example, the effects on relationships with partners and children were greatly overestimated

◘ Table 102-3
Reported amount of negative, neutral and positive consequences of disease, for different patient groups

Patient group	# of negative consequences	# of neutral consequences	# of positive consequences
Breast cancer (2–3 years; DCIS)	2.9	10.1	6.1
Breast cancer (2–3 years; invasive)	4.7	8.1	6.4
Breast cancer 5–10 years	2.3	7.1	8.3
Prostate cancer 5–10 years	2.7	7.4	9.7
Morbid obesitas	7.8	7.7	4.5
Infertility (women)	5.0	8.5	6.1
Addiction	10.9	5.7	3.3

by nurses, while physicians underestimated hair loss the most. The authors concluded that this observed lack of correspondence between patients and health-care providers may result in inappropriate provision of attention and health care. They argue that methods have to be developed to assess easily the main needs and worries of individual patients, which is an essential condition to be able to provide optimal care.

In conclusion, there is little doubt that chronic and life threatening disease may have a major impact on the patient. However, not all aspects of life are necessarily negatively influenced, and there may be great individual differences in what is perceived as most threatening and stressful. Health care providers cannot assume that every patient experiences his/her disease in the same way and that all patients can be treated equally. In order to provide optimal care, careful questioning the patient either face-to-face or with a structured questionnaire is needed in order to pay adequate attention to the specific concerns and worries of that individual patient.

3.3 Suffering

The alleviation of suffering is a chief objective of medicine, especially in the care of terminal patients. However, medicine also seem to apply interventions (e.g., chemotherapy) which increase suffering, rather than reducing it. Suffering can only be treated if it can be recognized and diagnosed. It involves not only mere symptoms or the process that threatens the patient, but also is related to issues like the perceived meaning of the symptoms and concerns about the future. The meanings and fears may be very personal and individual, so that even if two patients have the same symptoms, their suffering is likely to be very different.

Cassell (1982) wrote a seminal theoretical contribution about the nature of human suffering. The essence of his description is that suffering is “experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity” (Cassell, 1982, p. 639). Cassell also asserted that suffering may include pain but is not limited to it. His comparisons of pain versus suffering and his exploration of the concept *meaning* emphasize the importance of taking into account the whole person, when attempting to diagnose and operationalize suffering. This author also feels that because nursing and medicine have become highly technical and often quite depersonalized, there is hardly adequate attention for this aspect. The challenge therefore also is to design a valid method to assess suffering, taking into account the *personal meaning* an individual gives to the threats to his or her "personhood" and recognizing this aspect is critical to adequately understanding human illness and suffering. This personhood can be seen as a complex intermingling set of person features like personality and character, past life experiences, social environment, and cultural background. Consequently, the extent to which a disease affects the individual depends on this melting pot of person and environmental features. Therefore, it may not come as a surprise that there is a lot of individual variability in the degree of suffering given a certain specified objective disease severity. To illustrate this, Cassell refers to a young woman with breast cancer:

"This young woman had severe pain and other physical symptoms that caused her suffering. But she also suffered from some threats that were social and from others that were personal and private. She suffered from the effects of the disease and its treatment on her appearance and abilities. She also suffered unremittingly from her perception of the future" (Cassell, 1982).

Being aware of the relevance of suffering for medicine is one thing, the development of valid ways to diagnose or assess it is another. As Kleinman (1982) wrote: "Clinical and behavioral science research also possess no category to describe suffering. Symptom scales, survey questionnaires and behavioral checklists quantify functional impairment and disability, yet about suffering they are silent."

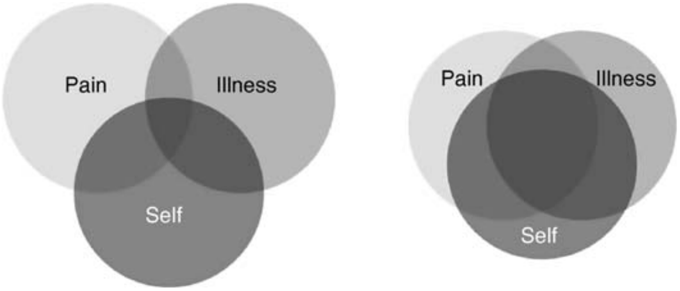
An interesting and possibly relevant model in this respect is the so called enmeshment model introduced by Pincus and Morley (2001). According to these authors, individuals have cognitive representations (schemata) of their self, their illness and their pain. They theorized that the experience of chronic pain related to the degree to which the three schemas of pain, self and illness over-lapped, leading, ultimately, to a form of enmeshment where the activation of elements from one would influence the other. A pathway, via the self, was hypothesized between the physical and psychological dimensions of chronic pain and it was the degree to which chronic pain disrupted the aspects of the person's schema of the self that determined the focus and degree of enmeshment: "the degree to which the chronically activated pain schema 'traps' negative aspects of the self. As a consequence, the pain experience is viewed in terms of its behavior and affective implications for the self and not just its sensory characteristics" (Pincus and Morley, 2001). To put it differently, "healthy" adjustment or adaptation involves separation of the schema for Self, Illness and Pain, whereas distress arises when the schemata for Pain and Illness become enmeshed with the Self-Schema (see ❯ *Figure 102-2*).

The graphical representation of the enmeshed model inspired Büchi and Sensky (1999) to design a simple visual method to assess coping and adjustment to disease: the Pictorial Representation of Illness and Self Measure (PRISM; Büchi et al., 2002; Büchi and Sensky, 1999). The PRISM was originally believed to assess coping. However, pilot qualitative research demonstrated that this instrument was probably measuring suffering, which is something more complex than just coping.

This measure breaks with tradition in that it does not contain any questions, but rather consists of a rectangular (A4 size) metal board, with a fixed yellow circle (7 cm in diameter) in the bottom right-hand corner. Patients are asked to imagine that the white board represents their current life and the yellow circle their "self." They subsequently receive a magnetic red

Figure 102-2

Schematic example of normal enmeshment versus distressed enmeshment (based on Pincus and Morley, 2001)



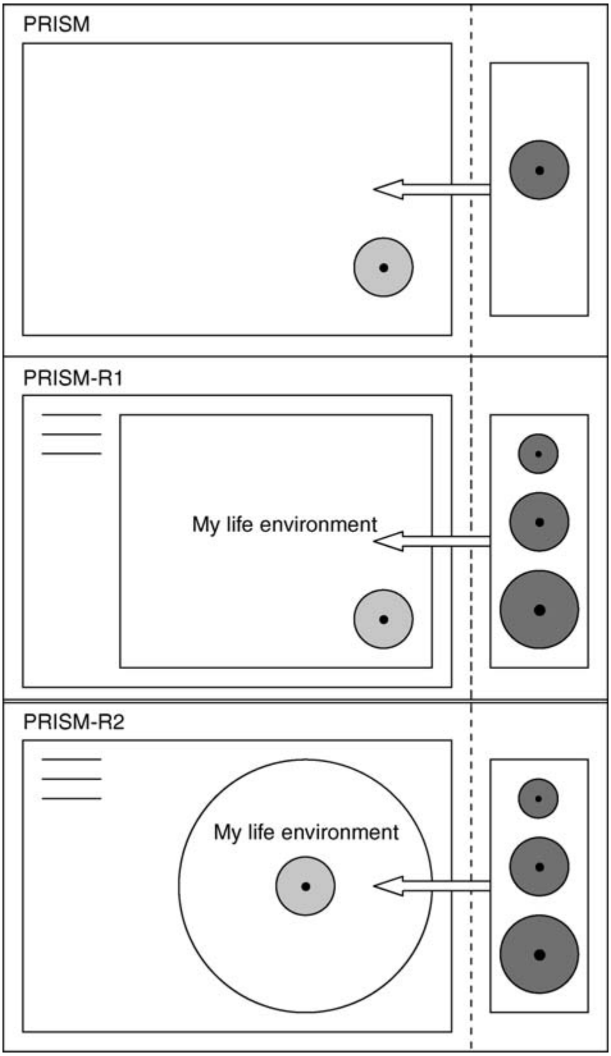
disk (5 cm in diameter), which represents their illness (illness-disk), and are asked to place the illness-disk on the board to represent the place of the illness in their current life (see the upper part of ➲ *Figure 102-3*). The patient receives oral standard instructions explaining the task. The PRISM is hypothesized to produce a graphical summary of the relationships between illness, self, and "life at the moment" which cannot be reduced to a single dimension. This summary is difficult to capture with questions because each individual will give different weights to a wide variety of factors which determine suffering. The quantitative measure derived from this application, the distance between the centers of both disks, is referred to as Self Illness Separation (SIS). It is assumed that patients have cognitive representations of their "self" and their illness and that healthy adjustment to the disease implies that there is a separation between the "self" and the illness schema.

Comments of patients completing the task revealed that the SIS measure is associated predominantly with patients' perception of the intrusiveness of the illness, its controllability, and the interference of the illness with salient aspects of everyday life. ➲ *Table 102-4* shows some examples of patients' comments patients corresponding to either low or high SIS. In essence, PRISM is a visual representation of the relationship between the person's "self" and his/her illness.

Recently, Wouters et al. (2008) have developed two modifications of the original PRISM task, the PRISM-R1 and PRISM-R2, because patients commented that the "size" of their disease could be perceived very differently. In addition, it was noticed that patients occasionally considered the middle of the A4 sheet as the central point in their life, rather than the self-disk. The major change of the first modification (PRISM-R1) therefore involved giving patients a choice of three different sized illness-disks (see the middle part of ➲ *Figure 102-3*). This modification resulted in an additional quantitative variable, referred to as Illness Perception Measure (IPM). The second modification (PRISM-R2) involved placing the self-disk in the middle of a large printed circle, rather than in one corner of a rectangular sheet as in the original PRISM to symbolize the centrality of the self-disk (see the lower part of ➲ *Figure 102-3*).

In three separate studies, the feasibility and psychometric qualities of the two revised versions of the PRISM was explored (Wouters et al., in press). Two studies were carried out with PRISM-R1. In the first one, the potential use of the PRISM-R1 as a generic measure for suffering by comparing results of five different patient groups was explored, and its validity

◘ Figure 102-3
Schematic example of the PRISM, PRISM-R1 and PRISM-R2. Reprinted with the kind permission of Heldref Publications, publisher of Behavioral Medicine



was examined. It was found that whiplash patients and women with fertility problems indicated higher suffering than lung, cancer, and psoriasis patients. In the second study the sensitivity to change of the PRISM-R1 was tested by comparing pre- and post treatment data of a group of whiplash patients participating in a multidisciplinary intervention program. As expected, after the intervention significant changes were detected, suggesting less suffering. PRISM-R2 was evaluated in a third study involving the collection of additional qualitative and quantitative data among morbidly obese patients seeking bariatric surgery. This latter study was designed to investigate the content validity and the convergent and divergent construct

Table 102-4

Examples of patient comments on their choice for positioning the "self" disk (SIS)

Themes	Low SIS statements: SIS $<$52 mm overlap with "self"	High SIS statements: SIS $>$52 mm no overlap with "self"
Impact of the patient's medical problem on daily life	My obesity interferes with everything: movement, work, mood (SIS 0 mm)	My obesity is something close to me. I carry it around all day. However, it doesn't control my life (SIS = 64 mm)
Impact of the medical problem on health status	For me it is very important to lose weight because of my back and feet complaints (SIS 0 mm)	My medical problem doesn't cause me psychological health problems, I am not ashamed of my appearance (SIS = 59 mm)
Attributed origin of the medical problem (self, other/something else)	I am the problem myself (SIS = 2 mm) Overweight is a problem beyond my power (SIS 29 mm) It is part of myself and part of others (harassments) (SIS 47 mm)	

validity of the SIS and IPM. SIS and IPM showed overlap, but also tapped specific, unique aspects of the perceived burden of disease. Further research is needed to unravel the specific elements addressed by both variables, and currently a study is being designed that focuses on the cognitive processes that respondents apply when making their choices concerning the disk size and the location. That information might contribute importantly to our understanding of this intriguing measure.

This measure is currently applied in a large multi-center study among diabetes patients. A pilot study learned that this measure was met with much enthusiasm by the involved diabetes nurses. All patients completed a computerized version of the PRISM-R2 and the results were used to start a conversation with the patient, asking him/her to explain why s/he choose for that specific size of the illness disk and why it was attached at that specific location. The nurses also asked what the ideal situation would be and what was perceived as main barriers to reach that ideal situation. Such information might not only very helpful to identify those patients that need extra support and attention, it will also contribute to a better understanding of the interpretation of this measure.

A final interesting theoretical issue concerns the precise the relationship between suffering and QOL. It is probably too simple to say that suffering is merely a very low QOL. In line with the ideas formulated by Cassell (1982, 1991), we come to the following preliminary hypothesis: in case of severe physical problems and limitations, the QOL will be determined to a large extent by being able to give meaning and to perceive benefits of one's condition. If a patient fails to meet these demands necessary for successful adaptation to the disease, a very low QOL, to be labeled as suffering is most likely the result. In contrast, when, in the same condition, the patient is able (and many patients appear to have this capacity!) to give meaning and to find benefits, the condition is set for a rather good QOL and maybe even personal growth. Further research is needed to investigate the validity of this model.

4 Conclusion

There can be little doubt that the QOL concept takes a central and increasingly important position in health care. This is evidenced, among others, by the strong increase in the number of publications on this issue. QOL is a main outcome when evaluating health care interventions. However, the term QOL is often mistakenly used interchangeably with related terms such as health status. In addition, for a better understanding of the dynamic processes that determine one's QOL, it seems useful to examine concepts such as illness-related stressors, illness impact and suffering. We also want to plea for assessment of QOL and/or the here discussed related concepts, in order to prevent health care providers from not fitting the care to be provided to the needs of the patients.

Summary Points

- The concepts HS (also known as health-QOL) and QOL are often used interchangeably which may easily induce confusion.
- Physical limitations or malfunctioning not always imply a poor QOL.
- In particular long term cancer survivors also report many positive effects of their disease on several aspects of their life.
- In order to understand the dynamics of the factors contributing to QOL, more research is needed with concepts like illness related stressors, illness intrusiveness or disease impact, and suffering.
- Failure to assess adequately the QOL and/or related concepts in patients may result in the provision of inadequate and not needed care, at the cost of attention for issues that seriously bother the patients.

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