

Quality of Life After Spinal Cord Injury

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ABSTRACT

Quality of life (QOL) is an often-used but it remains an ill-understood concept in medicine. Literature suggests 3 important approaches to operationalize and measure QOL: Health-related quality of life (HRQOL), well-being, and QOL as a superordinate construct. To measure the various instruments of HRQOL (SF-36 and Sickness Impact Profile) and well-being (Satisfaction With Life Scale and Life Satisfaction Questionnaire LiSat) are used. Domains on which QOL of persons with SCI lag behind QOL of the general population are identified. Overall, this paper suggests: (1) that inspection of the QOL measure used in a particular study is necessary to identify the domains of QOL that are measured, (2) that most measures lack sufficient evidence of reliability and validity, and (3) that longitudinal studies starting in the early phase of rehabilitation are necessary to reveal the course and predictors of QOL of persons with SCI.

Key Words: quality of life, spinal cord diseases, measurement, treatment outcome

INTRODUCTION

Few concepts in health care are as often used and at the same time poorly defined as 'Quality of Life' (QOL). McKeivitt et al¹ reported in a study on the awareness regarding the concept of QOL that a large majority (72%) of British health care professionals associated QOL with happiness. The other most often mentioned descriptions included elements of social (26%), physical (25%), or mental (18%) health or functioning. However, only 3% of these professionals were able to identify a QOL instrument measuring well-being and the most often mentioned QOL measures were the Medical Outcome Study Short-Form 36 (SF-36)² and the Nottingham Health Profile (NHP),³ which are not considered as measures of happiness. This discrepancy clearly illustrates the confusion concerning the concept of QOL and quite often the only way of finding out what conceptualisation of 'QOL' is particularly investigated in a study is to examine the content of the QOL measure used.

THE CONCEPT OF QUALITY OF LIFE

Despite this confusion and the complexity of the concept, the scientific community tends to acknowledge the existence of 2 main conceptualizations of QOL: (1) the *objective* approach, based on one's characteristics that can be objectively measured by an external appraiser and (2) the

subjective approach whose focal point is the person's emotional or cognitive assessment of the congruence between his/her life expectations and achievements.^{4,6} In this article, 3 ways of making the concept of QOL operational will be discussed: the health-related QOL approach (HRQOL), the well-being approach, and an approach in which QOL is seen as a superordinate construct that involves both HRQOL and well-being, and that is linked to the disability models.⁷ Two important other approaches of QOL are not discussed here for reasons of space. One is the societal approach in which so-called 'utility' measures like the EuroQol⁸ and the Quality of Well-Being Scale⁹ are used to compute 'quality-adjusted life years.' The other is the individual approach in which subjects are first asked to indicate what is important for them and then are asked to rate their functioning on these items, sometimes combined with an importance rating. Individual measures are for example the Canadian Occupational Performance Measure¹⁰ and the SEIQOL.¹¹ Both approaches are in-depth described by Dijkers.^{4,6}

HRQOL stems from the well-known definition of health by the World Health Organization, 'A state of complete physical, mental, and social well-being and not merely the absence of diseases and infirmity.'¹² One should notice the use of the confusing term 'well-being' in this definition. This broad 'biopsychosocial' conception of health has gained general acceptance¹³ and has led to the development of multidimensional HRQOL measures such as the Sickness Impact Profile (SIP)¹⁴ and the SF-36.² However, despite some consensus about the most relevant HRQOL domains (physical, mental, and social), some HRQOL definitions incorporate other aspects, like financial situation or spirituality.⁷

Well-being consists of 3 separate components: positive affect, negative affect, and life satisfaction.^{15,16} Affect is strongly correlated with mood, whereas life satisfaction refers to well-being as the 'subjective evaluation of the good or satisfactory character of a person's life as a whole.'¹⁷ This conceptualization of QOL is equivalent to terms like happiness,¹⁵ global well-being,¹⁸ or subjective well-being.¹⁹ From this point of view, health is not part of QOL but rather a predictor of QOL.^{20,21} Likewise, concepts used in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) model²¹ (disease, impairment, disability, and handicap) all influence QOL, mediated by personal factors like personality and coping, and by environmental factors like societal resources.²²

The superordinate construct of QOL includes both HRQOL and well-being in a broader definition of QOL,

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appreciating the distinction between objective and subjective approaches described earlier in this section. For example, McDowell and Newell²³ describe QOL as: 'both the adequacy of material circumstances and people's feelings about these circumstances. From this overall concept of QOL, Whiteneck²⁴ distinguished the concept of 'handicap' as being the objective and observable component of QOL, and the concept of 'life satisfaction' as the subjective perceptions of the quality of one's own existence.

The Concept of QOL and the Disability Models

Post et al⁷ proposed a conceptual model that integrates a superordinate approach of QOL with the ICIDH model of disablement.²² An upgraded version of this conceptualization using the International Classification of Functioning, Disability and Health (ICF)²⁵ as the basis is displayed in Figure 1.

The model consists of 4 main components: disease (not further described), the consequences of disease at different

levels, personal factors, and environmental factors. These components are also part of the ICF and disability creation process²⁶ models. Within the consequences of disease, 7 domains are distinguished and can be applied to the field of SCI. The upper 3 behavioural domains are the 3 ICF levels of body structures and function, activities, and participation. These domains can be assessed by observable deviations from normal functioning like paralysis of both legs, inability to walk, and being confined to one's house. The lower 3 elements are subjective domains focusing on perceptions of the person involved, which can only be reported by the individual. The seventh box is that of general well-being, which is not included in the ICF model.²⁷ Together, these 7 boxes cover the most relevant domains of QOL in the superordinate approach. As previously stated,²⁰ the personal and environmental factors can play a mediating role in the personal appraisal of the subjective dimensions and thus are predictors, but not parts of QOL. With this model it is possible to specify what kind of QOL is

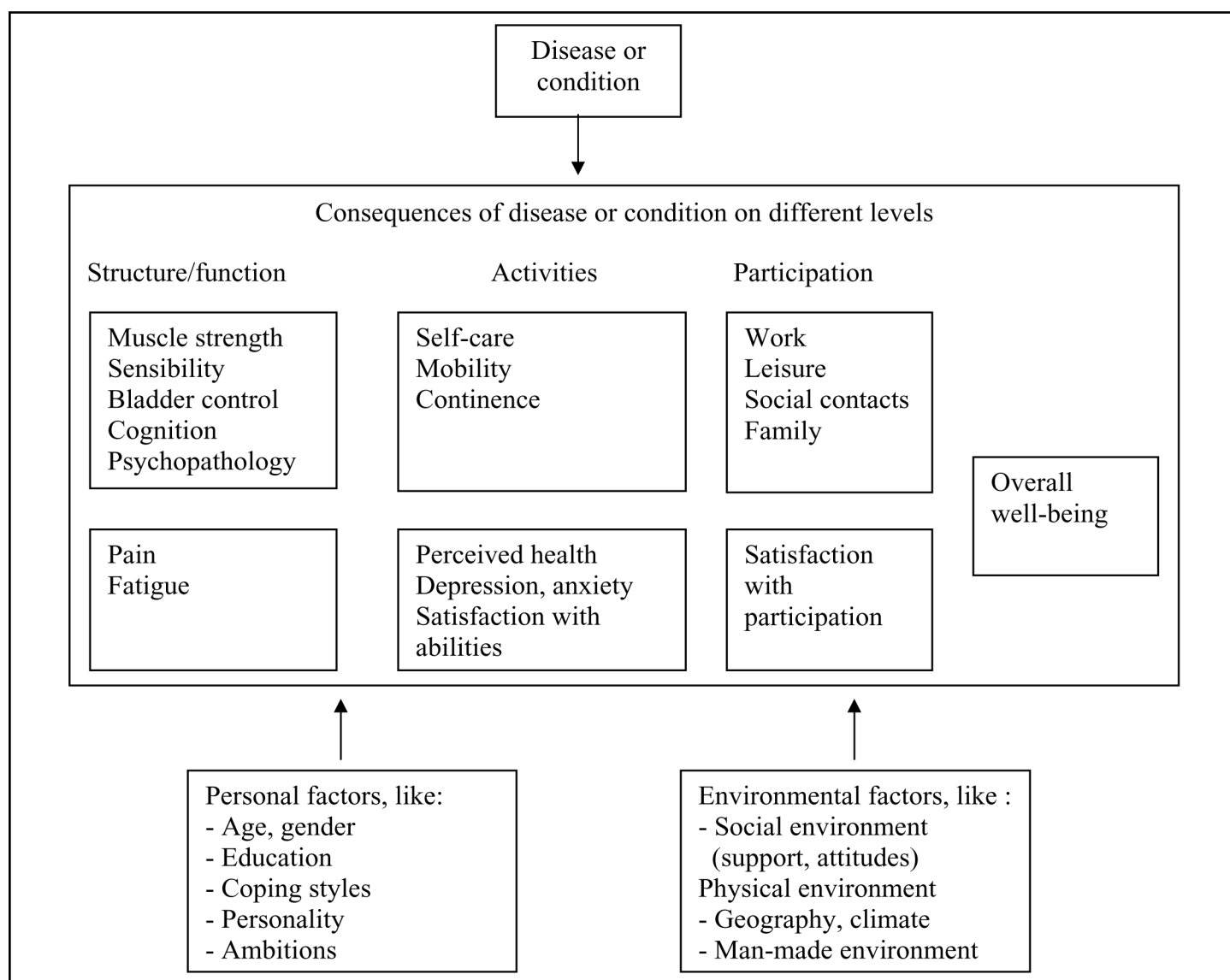


Figure 1. An ICF-based model of quality of life. Adapted with permission from Post MWM, de Witte LP, Schrijvers AJP. ⁷ Copyright 1999, Arnold.

investigated in different studies, and to compare the content of measures, QOL questionnaires and others, to examine which domains of QOL they essentially measure. For example, the 8 scales of the SF-36 can be related to this scheme. The physical functioning scale is part of the ICF activities component (behavioral and observable dimension) while the other 7 scales are part of the subjective appraisal of the ICF components. Body structure function (pain and vitality), activities (general and mental health), participation (social functioning, role limitations physical and emotional).

Participation and QOL are related concepts in all 3 approaches of QOL and their relationship is highlighted in the model. In the HRQOL and in the superordinate approach, both objective and person-perceived participation are aspects of QOL. Most HRQOL measures cover elements of person-perceived participation, for example, the Social Functioning scale of the SF-36² or the Work, Leisure, and Social Relations scales of the SIP.¹⁴ In the well-being approach, only the domain of over-all well being is considered as a QOL dimension and consequently participation is not seen as part of QOL but as a determinant of QOL.

Measurement of HRQOL

There are numerous measures of HRQOL. The measures most often used in SCI were developed for use in various diagnostic groups, the so-called generic measures,²⁸ of which the SF-36² and the SIP¹⁴ (the original 136 item version and the shorter 68 item version) are the most important. Other measures like the NHP³ or the WHO Quality of Life Questionnaire (WHOQOL-100; WHOQOL-BREF)^{29,30} have rarely been used in persons with SCI. The only SCI-specific HRQOL questionnaire to date has been developed in Sweden by Lundqvist et al.³¹ This measure is a combination of parts of well-established generic questionnaires (SIP, Hospital Anxiety and Depression Scale³², Mood Adjective Check List³³) and SCI-specific questions about, for example, being dependent on others, pain, and sexuality. According to the authors this measure could be used in routine clinical follow-up, but for research purposes they suggest to use the original questionnaires. Only the properties and use of the SIP and SF-36 in persons with SCI will be discussed here.

The SF-36 consists of 36 items in 8 scales (General Health, Physical Functioning, Pain, Social Functioning, Role Limitations due to Physical Problems, Role Limitations due to Emotional Problems, Mental Health, and Vitality) that can be clustered in 2 summary scores reflecting physical and mental health. Andresen et al.^{34,35} evaluated the SF-36 for use in persons with SCI as moderately positive. Respondents generally found the burden of filling in the questionnaire acceptable but the physical functioning scale has been found to be offensive to individuals with mobility impairments because 5 of the 10 items refer to climbing or walking. Researchers have proposed alternatives such as omitting the 10 physical functioning items³⁶ or administering the SF-36 via computer adaptive testing so that it begins

with the easiest questions and only asks relevant questions.³⁷ Another attempt to make the SF-36 more relevant was to replace 'walking and climbing' by the word 'go',³⁵ but this strategy changes the meaning of the items from assessing limitations in performing physical activities to how they have adapted to accomplish these types of activities. Moreover, to answer the questions *in the context of health* can be problematic as some persons with SCI will distinguish health from disability. People perceive themselves as healthy, defining SCI and its consequences as a disability, and not as a disease. Tate et al.³⁸ noticed that only 50% of people with SCI always interpreted health as including the effects of their injury while 20% never included it.

The SIP is a measure of behavioural consequences of disease consisting of statements (136 or 68) like 'I cannot walk at all' or 'I stay at home most of the time' and the respondent indicates whether or not they apply to his/her situation and if it is the consequence of a health problem. The SIP68 scales (Somatic Autonomy, Mobility Control, Mobility Range, Social Behaviour, Psychic Autonomy and Communication, and Emotional Stability) can be merged into 3 health dimensions reflecting physical, mental, and social health status.³⁹ Post et al.⁴⁰ found the SIP68 valid for use in persons with SCI. They however had to change the instruction in '...the consequence of a health problem or disability,' and had to develop a recoding procedure to deal with several questions about walking difficulties that are not applicable to persons who cannot walk at all.⁴⁰ Nanda et al.⁴¹ showed good test-retest reliability in persons with physical disabilities. Nonetheless, these studies suggested that the SIP68 and the SF-36, both supposed to measure HRQOL, actually are quite different, measuring 'functional health' and 'perceived health' respectively. Although both are patient-reported measures, one important difference is that the SIP is a more 'objective' measure than the SF-36, because it only contains possibly affected behaviours while the SF-36 also contains questions about pain, energy, and emotions. This difference is also seen in the correlations between scales of these questionnaires and other measures. SIP68 scales show stronger correlations with neurological impairment and physical disability than SF-36 scales. The latter, on the other hand, show stronger correlations with measures of perceived health, mental health, and well-being.⁴²

Measurement of Well-Being

Many different well-being scales have been used in SCI research.²⁰ Diener's Satisfaction With Life Scale (SWLS)¹⁵ is the most often used measure and is now part of the US SCI Database.⁴³ The SWLS consists of 5 items, each rated on a 7-point Likert scale (strongly agree - strongly disagree). The SWLS showed good internal consistency and test-retest reliability.¹⁶ A disadvantage of the SWLS is that it results in one total score only so that it is not possible to differentiate between domains that persons with SCI may be more or less satisfied with. Several authors used one-item questions to assess life satisfaction such as 'How would you rate your

QOL these days?^{44,45} Typically, scores on one-item measures are strongly correlated to scores on multi-item measures. However, one-item measures are inferior from the statistical point of view because they are more vulnerable to random error and because it is impossible to examine the amount of random error in scores on only one item.⁴⁶

An example of a domain-specific questionnaire is Fugl-Meyer's Life Satisfaction Questionnaire (LiSat).^{47,48} This instrument exists in different versions (LiSat 9, LiSat 11) and contains one question about satisfaction with life as a whole and various questions about satisfaction with life domains like self-care ability, vocational situation, sexual life, and relationships with friends and acquaintances. Each item is answered with a 6-point rating scale (very dissatisfying – very satisfying). Fugl-Meyer and associates only reported percentages of persons being satisfied/very satisfied (item scores 5,6) on separate items, but it is also possible to compute a total score with acceptable internal consistency reliability.⁴⁹ A more comprehensive domain specific measure is the Quality of Life Index⁵⁰ measuring both satisfaction and importance regarding various aspects of life. Importance ratings are used to weigh satisfaction responses reflecting satisfaction within the 4 domains of life (health and functioning, psychological/spiritual, social and economic, and family). Good psychometric properties were reported, mostly in groups of people with cancer, heart and renal disease, and a specific scale has been developed for individuals with SCI (Ferrans & Powers: <http://www.uic.edu/orgs/qli/index.htm>). To date, insufficient evidence for the reliability and validity of the QLI-SCI version exists although a first study showed promising results.⁵¹

QUALITY OF LIFE IN PERSONS WITH SCI

Many rehabilitation clinicians and researchers have been surprised by the results of QOL studies in persons with SCI. These studies usually show that QOL of this group is better than expected and shows only little relationship with the severity of the SCI. Studying HRQOL, usually with the SF-36, most studies showed that persons with SCI have, not surprisingly, on average much lower scores on the Physical Functioning and Role Limitations Due to Physical Problems scales than the general population.^{34,42,52-54} Scores on Pain, General Health, and the physical dimension score were also lower in these studies, but deviating results were seen for scores of Mental Health, Vitality, and Role Limitations due to emotional problems and the mental dimension score was not lower in SCI than in the general population in all studies in which this score was computed.^{34,52-54}

Several studies have compared well-being of persons with SCI to that of the general population. These studies show that the average scores of SCI groups are somewhat, but not much lower than those of general population groups.²⁰ In a later review it was estimated that most studies found a standardized difference (effect size) between 0.5-1.5 SD from the population, which represents a 'large effect' although one might have expected larger differences

for persons with such a serious condition.⁵⁵ A methodological weakness of these comparisons is that researchers rarely use age- and sex-matched comparison groups. A lower satisfaction with life, in general, of persons with SCI was found nonsignificant after adjusting for age and sex differences.⁴⁹ The domains of life that caused most dissatisfaction in this study were self-care ability (in persons with tetraplegia), vocational situation, and sexual life. Brown et al,⁵⁶ using a measure that consisted of different items, found most discrepancy between needs of persons with SCI and the general population for the domains health and personal safety, work and active recreation.

Predictors of QOL After SCI

Leduc et al⁵³ studied predictors of HRQOL in a large group of persons with SCI in Quebec and concluded that younger age, employment, and lack of hospitalization in the previous year were associated with better SF-36 scores. Severity of the impairment was in all studies related to the physical health scales of the SF-36, but deviating results were seen concerning the relationship between severity of impairment and the mental health scales.^{34,42,52-54} It is not clear why the mental health scores of the SF-36 are not related to impairment severity. It is unlikely that this is caused by poor measurement properties of these scales, as this lack of relationship is also seen when depression measures like the Beck Depression Inventory or the Patient Health Questionnaire-9 are used.^{57,58}

As previously hypothesized,^{59,60} Dijkers²⁰ confirmed with a meta-analysis the minimal or weak impact of impairment severity and activity limitation on well-being (mean correlation -0.05 and -0.21, respectively) while participation restrictions (handicap) revealed moderate correlations with well-being (range -0.17 to -0.48 depending on the specific domain selected). It has been suggested that impairments due to SCI do not affect well-being directly, but rather through their impact on activities and participation.⁶¹ In other words it might be hypothesized that if participation is not affected after SCI, for example due to re-education, sufficient equipment, and adaptations or due to otherwise favourable conditions, it is likely that well-being will not be affected. It has also been shown that physical fitness and wheelchair skills of persons with SCI predict their level of participation and quality of life.^{62,64} Other relevant determinants are time since injury, personal factors, and environmental factors like social support⁶⁵ and perceived environmental accessibility.⁶⁶

As these relationships are complex and involve many variables, they require advanced statistical methods but unfortunately, few researchers have analysed the interrelationships between consequences of SCI and QOL other than with regression analyses. A path analysis model that emerged from previous work is shown in Figure 2 (redrawn from Post et al⁶¹).

In this figure, relationships between consequences of SCI are illustrated and, life satisfaction (LSQ total score) is

predicted by social health status (two SIP68 scales), which is in turn predicted by physical and mental health status (also SIP68 scales), which are predicted by injury characteristics and demographic characteristics. Using structural equation modelling, we demonstrated that this model fitted the data. The arrows in the model are significant regression coefficients (bold if greater than 0.40). It is seen that there are no direct relationships between impairments and life satisfaction. Also, this figure illustrates the impact of secondary conditions (like pressure sores, urinary tract infections, spasticity) on mental and social, but not on physical health status. Life satisfaction was predicted (44% explained variance) by better social health status, better mental health status, younger age, and being married. Using a similar approach in a study on aging and QOL, McColl et al⁶⁷ found that QOL is affected directly or indirectly by age, health, and disability-related problems. Level of injury was, like in our study, only an indirect predictor of QOL through a relationship with disability-related problems.

One serious limitation of such studies, and most other rehabilitation studies, is that personal and environmental factors were not included in the same analyses. Personal factors like personality, disease cognitions, and coping behaviour influence well-being,⁶⁸ and it is possible that relationships between, for example, mental health and life satisfaction are mediated by personal factors or decrease in importance when personal factors are entered in explanatory models.

CONCLUSION

The concept of QOL consists of different domains that are not equally affected by having a SCI. The content of QOL assessment tools also differ and it cannot be assumed that results of different measures are equivalent. Available literature confirms hypotheses generated by the ICF model that, moving from left (body structure and function) to right

(participation), (1) differences between functioning of people with SCI and the population become smaller, (2) relationships with severity of injury become weaker, and (3) the influence of personal and social factors become stronger. Nevertheless, most studies show significantly lower QOL scores on all domains of persons with SCI compared to the general population, although the differences are not as large as one might expect.

Despite the large number of studies on QOL after SCI, our knowledge of how well-being after SCI develops and what factors have a positive or negative influence on the course of QOL is still limited. There is a lack of longitudinal studies, especially in the initial phase of the injury. There is also a need for studies that incorporate simultaneously disability, personal and environmental factors as predictors of quality of life.

The ultimate goal of rehabilitation might be described as reducing disabilities in order to minimize handicaps.⁶⁹ We showed that participation is an important predictor of the patient's perception of overall well-being. Physical therapy (PT) aimed at, for example, optimizing mobility is an important tool to optimize participation and thereby QOL of persons with SCI.

Is it possible to suggest a more significant role of PT vis a vis HRQOL...Doesn't the PT have to incorporate an important outcome? A difficult issue, which would require taking into consideration different factors such as: (1) the role of this rehabilitation professional that varies from country to country, for example, the role of PT in the Netherlands might be different from that in America; (2) the intervention settings (eg, acute care vs community rehabilitation) which do not focus on the same therapeutic objectives; and (3) the clienteles (eg, pediatric, geriatric, or palliative care) which require different therapeutic approaches. Generally speaking, the use of QOL as a rehabilitation outcome should transcend any disciplinary approach and be part of a compre-

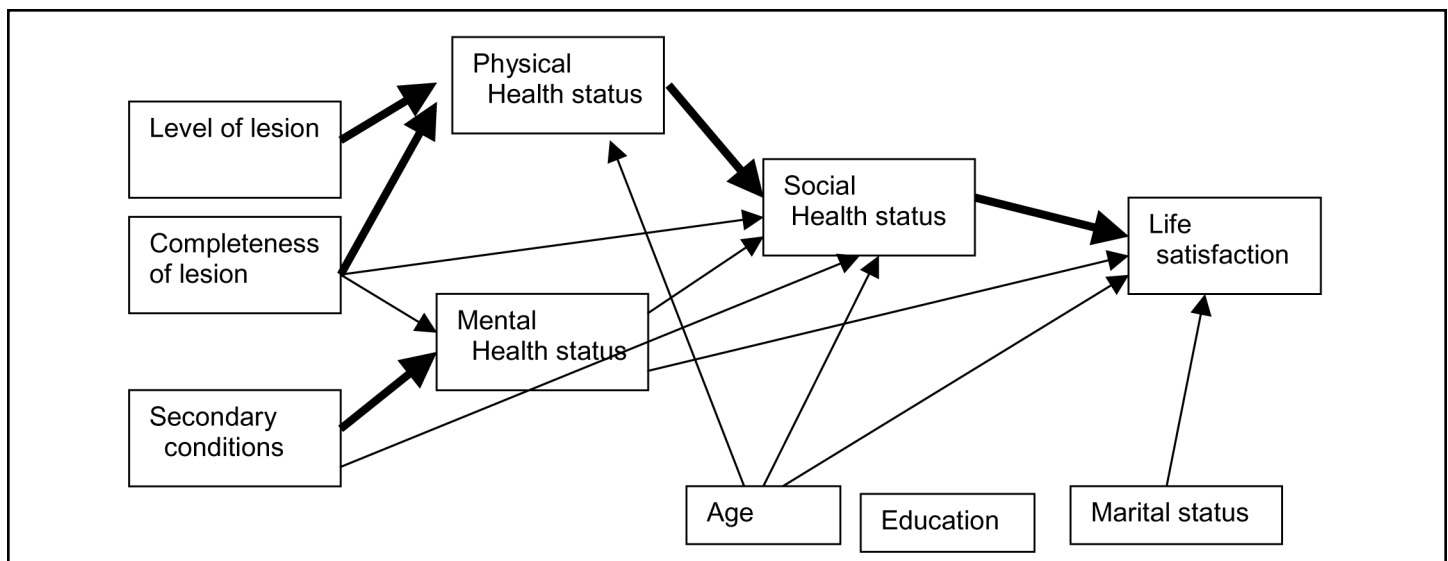


Figure 2. Path model of predictors of well-being of persons with SCI. Adapted with permission from Post MWM, de Witte LP, Van Asbeck FWA, Schrijvers AJP.⁶¹ Copyright 1998, W.B. Saunders.

hensive multidisciplinary process that relies on various interventions and professionals to reach the ultimate goal: an optimal level of QOL for any person with disabilities. Nonetheless, the discipline-specific objectives can be inferred to contribute to the enhancement of QOL and the use of the disability model (eg, ICF, DCP, etc) as demonstrated with the superordinate approach of QOL is certainly a suitable way to ensure a valuable contribution of PT to QOL in individuals with SCI.

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