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IMPORTANCE AND ATTAINMENT OF LIFE VALUES AMONG DISABLED AND NON-DISABLED PEOPLE

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ABSTRACT. How do disabled persons evaluate their life situation? To address this issue, importance and attainment ratings of 82 different life values as well as mood ratings were collected from 325 chronically ill and/or disabled persons and 504 non-disabled persons. Both groups largely agreed on what is important in life. The disabled persons, however, gave lower importance ratings on functions related to health and mobility. The attainment and mood ratings were in general slightly lower for the disabled persons. The attainment ratings for health and mobility were markedly lower. The concordance between rated importance and attainment across different life values was positive in both groups. This measure was also positively related to mood in both samples. It was suggested that disabled persons adjust to their life situation by de-emphasizing the importance of the physical functions affected by the disability and through habituation.

Key words: adjustment, chronic illness, coping, disability, mood, quality of life.

INTRODUCTION

Issues relating to quality of life are increasing concerns for medicine, rehabilitation and health care to obtain a more global understanding of patients' satisfaction with life. Measures of life quality concern people's subjective experiences of their life situation, in contrast to the more objective "bio-physical" outcome measures traditionally used in the medical disciplines.

Empirically, the research on quality of life most often has focused on the extent to which people experience their attainment of various states that are commonly regarded as desirable, like health or good social relations (5). However, since people have different views of what is important in life, a fair picture of how people evaluate their life situation is only obtained when both the subjective evaluations of importance and attainment of the different areas of life are considered (16). Thus, satisfaction with life could conceptually be viewed as a function of the distance between subjective importance of life values and perceived attainment. The smaller the gap, the greater is the satisfaction with life (13).

According to this view, unrealistic strivings might be as much a threat to a high life quality as are bad conditions. However, most people tend to adjust their values and strivings to what is possible (14). Likewise, people seem to adapt over time to both good and bad conditions through a change of reference standards (3, 4).

Wright (20) in particular, has stressed that adjustment to disability is a matter of arriving at a value change, including a subordination of the physique and an enlargement of the scope of values. Although examples of such value changes are easy to find in interviews with disabled patients, e.g. "due to my disability I have learnt to appreciate the things in life that really matter" (20), there are few empirical studies that have tried to investigate these existential adjustment processes. One exception is a study by Stensman (19), who found that the functions severely mobility-disabled persons lacked most compared to non-disabled, were those that they also rated as relatively less important.

The purpose of the present study was twofold: first, to further investigate possible differences in life values between a chronically ill and/or disabled group and non-disabled group; and second to relate the congruence between attainment ratings and importance ratings of these values to subjective well-being. The aim is to shed further light on how disabled persons adjust to their losses by means of changing their value orientation.

Table I. *Classification of changes in experienced attainment and importance of life values*

Importance change	Attainment change		
	−	0	+
+	Accentuating lost benefits	Accentuating unchanged benefits	Accentuating new benefits (exploitation)
0	Non-acceptance of lost benefits	No perceived change (habituation)	"Non-acceptance" of new benefits
−	De-emphasizing lost benefits (acceptance)	De-emphasizing unchanged benefits	De-emphasizing new benefits

−, decrease; 0, no change; +, increase.

Table I shows various theoretical possibilities of how the attainment and importance ratings of different life values may change over time for persons who have become disabled. The possibilities are of three major types. First, it may occur that neither importance nor attainment ratings change (see the middle entry of Table I: 0, 0). This may be the case for life values that are not seen as being connected with the disability. It may also occur that disabled persons habituate over time to some effects of the disability, especially when the effects are moderately strong (e.g. if the economic standard of living is slightly reduced). As a result of habituation, no lasting changes in attainment and importance may occur. Second, in order to adjust to the effects of the disability the disabled person may reorient his or her values (i.e. re-evaluate the importance of certain values). He or she may accentuate those values that are still attainable (entry +, 0) or even easier to attain than before the disability occurred (entry +, +). This type of adjustment may be denoted exploitation of existing possibilities. Conversely, the disabled person may de-emphasize the value of benefits that have been lost (entry −, −). In this case the adjustment may be seen as acceptance. Both of these types of value-reorientation are found in the study by Stensman (19). Third, the disabled person may fail to reorient his or her values in line with changes in life situation. He or she may even accentuate the value of lost benefits (entry +, −).

METHODS AND SUBJECTS

Selection of values

The respondents were asked to rate both the importance and the attainment of 82 statements concerning different life values. Of these, 43 tapped general life values (e.g. security, social affiliation, a satisfying job, etc.). These were selected from previous studies by Montgomery et al. (12). The other 39 questions related more specifically to health and effects of being chronically ill and/or disabled (e.g. being able to move without problems, being able to manage daily hygiene, being able to go to the theatre, restaurants, exhibitions, etc.).

Questionnaire contents

Background variables. The questionnaire included items concerning the respondents age, sex, marital status, education, profession, number of children, access to car, housing, general health status, self-reports of diagnosis, impairments and complaints.

Questions about the attainment of life values. The respondents were first asked to rate the extent to which each of the 82 statements gave a valid description of his or her life situation (e.g. "I have a secure life", etc.). The ratings were to be made on 100-mm graphic visual analogue scales (VAS) with the end-points defined as "Not at all" and "To a very large extent".

Questions about the importance of life values. The respondents were next presented with the same 82 life values, but this time they were phrased in infinitive form (e.g. "To have a secure life", etc.). The respondents were here asked to rate how important the circumstances referred to in each statement were for attaining what he/she wanted in life. The ratings were also made on 100-mm graphic VAS, but with the extremes defined as "Unimportant" and "Immensely important".

A mood adjective check-list (MACL). The final scale was a 71-item mood adjective check-list, which has been widely used in Sweden as a measure of emotional well-being and is fully described elsewhere (1, 2, 18). Briefly, it measures six bipolar mood dimensions labelled pleasantness, activation, calmness, extroversion, social orientation and control. The scores on these dimensions were aggregated to form an overall index of emotional well-being.

Subjects

Disabled group. The sample of disabled persons was selected from members of the Swedish Association of Neurologically Handicapped (NHR). The questionnaire was mailed to all registered members living in Göteborg and surrounding areas. Letters were also enclosed from the research group, providing information about the investigation, and from the local council of NHR, giving their support to the investigation, and an envelope with free postage for mailing back the questionnaire. The NHR members were also informed and encouraged to participate in the study during their annual meeting in 1992, as well as in an announcement in their newsletter. Full anonymity was guaranteed to those who participated in the investigation. Of the 600 who received the questionnaire, 325 filled it in and mailed it back. A drop-out analysis was not possible to perform because of the confidentiality of their membership register. This group will henceforth be referred to as the disabled group.

Self-reported diagnoses and complaints. The following diagnoses were reported in the disabled group: multiple sclerosis (36%); fibromyalgia (12%); muscle dystrophy (7%); stroke (6%); other muscular diseases (6%); myasthenia gravis (4%); Parkinson's disease (3%); spinal cord injury (3%) and cerebral palsy (3%). Twenty-five patients (7%) did not specify their diagnoses. The mean duration since the first occurrence of the illness/disability was 15.9 years (SD = 12.7). The following types of self-reported disabilities and symptoms were most common: impaired mobility (68%); mental, intellectual and communicative impairments (23%), e.g. difficulties to concentrate, memory problems, problems with nerves, problems to orientate oneself, problems with speech, reading and writing; pain (13%) and impaired vision (9%).

Control group. A sample of 1000 persons living in the same part of Sweden was randomly selected from the Swedish census register, approximately representing the general population. The questionnaire, a letter giving information about the investigation and a stamped self-addressed envelope for mailing back the questionnaire was mailed to each person. Full anonymity was guaranteed. Two further mailed reminders were sent to those who did not respond within 3 weeks. A total of 504 persons finally filled out the questionnaire. A drop-out analysis revealed no significant age differences between responders and non-responders, but there was a tendency for a higher response rate among the females (χ^2, $p = 0.053$).

Demographic differences between groups. The proportion of females in the disabled group was significantly higher than in the control group (64% in the disabled group were females compared to 54% in the control group; χ^2, $p = 0.015$). There was also a significant difference in the age distribution between the two samples (t-test, $p < 0.001$). The mean age was 51.6 years (SD = 13.9) in the disabled group and 42.0 years (SD = 14.7) in the control group.

Statistical analyses

Factor analyses of life values. Initially, separate principal component and maximum likelihood factor analyses with oblique rotation (9) were performed on the attainment ratings of the 82 life values across both groups of respondents. The attainment ratings were chosen in this initial step to identify meaningful and homogeneous factors because of the greater variance characterizing these ratings. Three strategies were used to determine the number of tentative factors to retain – Cattell's scree plot (6), the Kaiser criterion (10) and meaningfulness of factors (9). The factor structure that was judged as the best compromise among these criteria was then validated on the importance ratings. Principal component and maximum likelihood factor analyses with oblique procrustes rotation was performed in these analyses, with the pattern matrix from the attainment ratings as the target matrix. Procrustes rotation is a simple kind of confirmatory factor analysis that tries to reproduce a hypothesized factor pattern (the target matrix) as closely as possible and still account for the same amount of the variance of the correlation matrix as before rotation (7, 9, 17). In all factor analyses list-wise deletion of missing values was used. Thus, the analyses on the attainment ratings were based on the complete ratings from 580 subjects and on the importance ratings from 653 subjects, which in both cases are well above the recommended item/subject ratio (9).

Index constructions of life values. For the construction of index variables for the attainment and importance ratings, respectively, individual factor scores were created by computing the mean for each subject on those variables that loaded above 0.30 in the corresponding factors from both the attainment ratings and the importance ratings (see Table II).

Concordance measure. To estimate the degree of concordance between rated importance and attainment of life values an index was computed for each individual, by individually correlating both of these ratings for the 82 life values, and then transforming the obtained coefficients to Fischer's Z.

RESULTS

Factor analysis

A factor structure of 10 factors was judged to be the best solution in the initial analyses of the attainment ratings. Together they accounted for 54% of the variance of the 82 items. Cattell's scree plot (6) flattened out after the 10th factor, all 10 factors also had eigenvalues above one (10), and the factors were regarded to be homogeneous in content. The statements with factor loadings above 0.30 (semipartial correlations between variables and common factors) are shown in Table II.

The corresponding factor loadings for the importance ratings after procrustes rotation are also shown in Table II. This solution accounted for 52% of the variance of the 82 items. The tests of the number of factors to be retained revealed basically the same results as for the attainment ratings. Factor-intercorrelations as well as the amount of variance explained by each factor were also very similar in both types of ratings.

As can be seen in Table II the contents of the factor solutions were quite similar for both types of ratings and the 10 factors of life values were labelled *harmony*, *positive relations*, *involvement*, *mobility*, *communication*, *knowledge*, *responsibility*, *comfort*, *religion* and *health*. The homogeneity of the factors, computed by Cronbach's alpha (9), was high or moderate for both types of ratings across both groups of respondents, ranging from 0.87 to 0.49. Their relative magnitude was also roughly the same across both types of ratings and subjects groups.

Table II. *Factor loadings[a] for the attainment and importance ratings[b] across both samples*

Factor 1: Harmony
I can disregard the negative things in life (0.60, 0.43)
I enjoy the present moment (0.56, 0.44)
I accept my limitations (0.53, 0.31)
I accept that it's not possible to control everything (0.53, 0.48)
I can take it easy (0.49, 0.39)
I appreciate what I have and can do (0.44, 0.43)
I make the best of misfortunes (0.43, 0.56)
I have a positive view of life (0.39, 0.46)
I appreciate the simple things in life (0.38, 0.51)
I am independent (0.32, 0.35)

Factor 2: Positive relations
I am loved (0.68, 0.58)
I lead a good family life (0.57, 0.46)
I feel physical closeness to a partner (0.60, 0.35)
I am happy (0.54, 0.37)
I lead a secure life (0.48, 0.38)
I feel that others care for me (0.46, 0.52)
I can feel and express my love (0.40, 0.52)
Those nearest me lead a good life (0.35, 0.33)
Others help me (0.34, 0.33)

Factor 3: Mobility
I can manage everyday activities on my own (0.70, 0.57)
I can move unhindered (0.69, 0.61)
I can do my personal care without help (0.66, 0.52)
I can exercise and keep in good trim (0.55, 0.37)
I am free from physical hindrances (0.52, 0.57)
I am efficient (0.34, 0.35)

Factor 4: Involvement
I am involved in something (0.51, 0.42)
I develop as a person (0.46, 0.53)
I have life and activity around me (0.41, 0.36)
I experience togetherness with others (0.41, 0.34)
I have a career and am successful (0.40, 0.42)
I lead a diversified life (0.40, 0.41)
I have a satisfying job or occupation (0.39, 0.34)
I am creative (0.37, 0.45)
I have dreams and visions (0.35, 0.40)

Factor 5: Communication
I can use all of my senses (0.60, 0.61)
I can speak and communicate with others (0.5)
I can see (0.54, 0.60)
I can think and remember clearly (0.53, 0.51)
I can hear (0.52, 0.65)

Factor 6: Knowledge
I am well-educated (0.64, 0.47)
I have knowledge (0.62, 0.57)

Factor 7: Responsibility
I am orderly (0.63, 0.52)
I am responsible (0.58, 0.51)
I am honest (0.54, 0.48)
I have self-discipline (0.48, 0.40)

Factor 8: Comfort
I have a higher material standard (0.59, 0.57)
I have enough money (0.57, 0.49)
I have good housing (0.50, 0.50)
I lead a comfortable life (0.40, 0.36)

Factor 9: Religion
I am religious in my own way (0.72, 0.71)
I believe in God (0.70, 0.76)

Factor 10: Health
I am good-looking (0.51, 0.38)
I am free from physical pain (0.49, 0.37)
I am in good health (0.47, 0.32)

[a] Semipartial correlations between items and common factors. The factor loadings for attainment and importance ratings are given in that order within parentheses after each item description.

[b] Only those items that loaded above 0.30 on both types of ratings are included. The item descriptions are abbreviated translations from Swedish of the attainment statements.

Attainment and importance of life values

Figure 1 shows that the disabled group tended to give lower attainment ratings compared with the control group. For one index variable—*religion*—the disabled gave higher ratings than the control group. The differences were statistically significant (t-test, $p < 0.05$) for all index variables except *knowledge*. However, the difference was quite small ($<5\%$ of the scale) for *religion*, *comfort*, *responsibility* and *harmony*. Moderately large differences (5–15% of the scale) were found for *communication*, *involvement*, and *positive relations*. Substantial differences ($>20\%$ of the scale) were found for those variables that concerned physical effects of disabilities, namely *health* and *mobility*.

The importance ratings (see Fig. 2) also tended to be lower for disabled group than for the control group although the differences were considerably smaller. The importance ratings among the patients differed most from the control group in those areas in which the perceived losses were most profound, namely *health* and *mobility*. For two index variables—*religion* and *comfort*—the disabled gave significantly higher importance ratings than the control group. No significant differences (t-test, $p < 0.05$) were found for *harmony*, *knowledge* and *responsibility*.

Age and sex differences

No significant correlations were found between sociodemographic variables (age and sex) and index constructions or mood ratings, except for importance and attainment of *religion* (higher values for older people, and for females), attainment of *mobility* and *health* (lower values for older people), and importance of

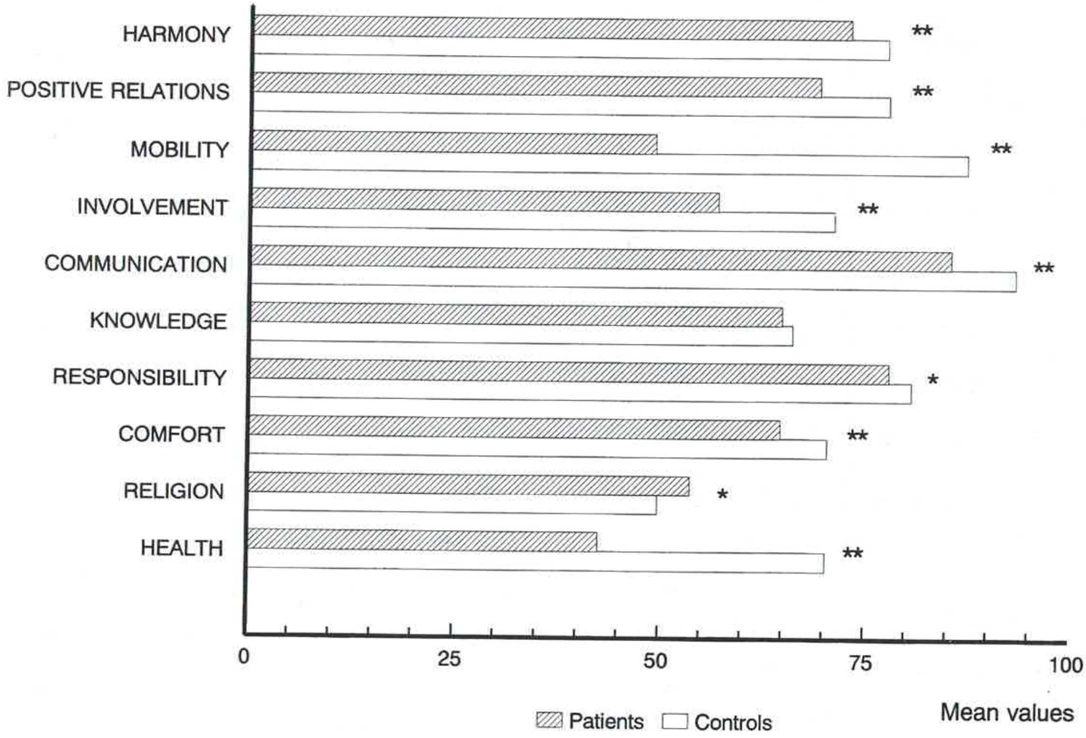

Fig. 1. Means of attainment ratings of the 10 index variables measuring values of life; * $p < 0.05$; ** $p < 0.01$.

harmony and *positive relations* (higher values for females).

Changes across time

Figure 3 shows correlations between self-reported duration of the disability and attainment/importance ratings for the 10 dimensions of life values. The correlations with the attainment ratings were not significant for any of the life values except *mobility* (negative correlation). There was, however, a tendency for positive correlations between disease duration and the attainment ratings of *harmony*, *positive relations* and *religion*.

The correlations between importance ratings and duration of disability were predominantly negative, reaching significance for *positive relations*, *mobility*, *involvement*, *communication*, *responsibility* and *comfort*. A positive correlation, though not significant, was found for *religion*.

Congruence between importance and attainment and its relation to mood

The control group had a significantly (t-test, $p < 0.01$) more positive mood level (Mean = 3.17, SD = 0.40) compared to the disabled group (Mean = 3.00, SD = 0.52).

The concordance measure between importance and attainment ratings (see Method section) was significant ($p < 0.01$), for both the control group (r = 0.53) and the disabled group (r = 0.44), indicating that both groups generally perceived that "they have what they find important". The difference in congruence between the groups was not significant.

It was also found that the degree of concordance between importance and attainments ratings was significantly related to mood in both samples (t-test after transformation to Fischer's Z, $p < 0.01$). In the disabled group the concordance index among the 25% (Q1) with the lowest mood was 0.27 compared to 0.54 among the 25% (Q3) with the highest mood. The corresponding values for the control group were 0.38 and 0.67, respectively.

DISCUSSION

The overall results regarding the effects of being disabled on perceived importance and attainment of life values indicate that a chronic illness and/or disability affects most life areas. The attainment ratings

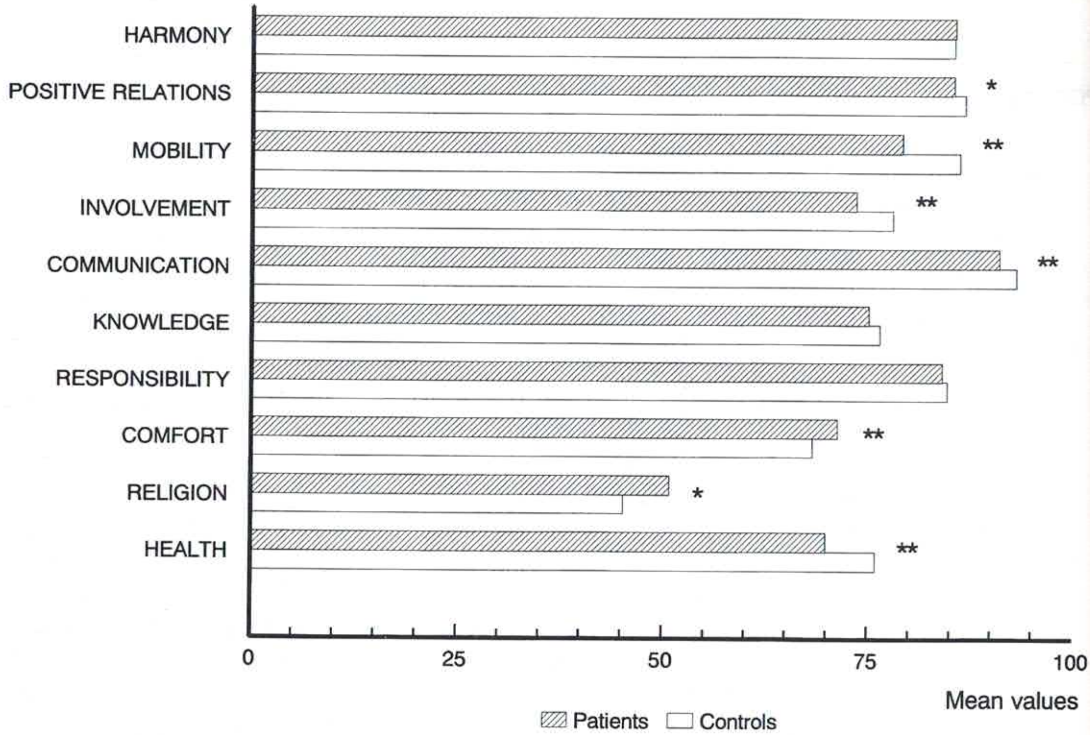

Fig. 2. Means of importance ratings of the 10 index variables measuring values of life; * $p < 0.05$; ** $p < 0.01$.

were lower in all life areas except *religion* and *knowledge*. However, substantial losses were experienced only in those life areas that concerned physical effects of the disability—in this case perceived *mobility* and *health*. Also the importance ratings of the examined life areas tended to be generally lower, except for *comfort* and *religion*, but these group differences were of lesser magnitude. Those areas in which the perceived losses were most profound (*mobility* and *health*) were also the areas in which the importance ratings differed most compared to the control group, giving evidence that the disabled persons tended to adjust to their losses by de-emphasizing the value of their losses. The importance ratings of *mobility* were also negatively correlated to disease duration. With regard to the other life areas the value orientation of the disabled persons and the control group was more similar, suggesting that on the whole disabled persons want the same things in life as non-disabled persons do.

It was also found that the degree of concordance between importance and attainment ratings was related to mood in both samples, indicating that subjective well-being, at least partially, involves finding a balance between values and possibilities. However, the degree of concordance was smaller in the disabled group, which could indicate that the disabled persons realistically perceived their losses, and were not completely able to adjust or habituate to them.

A corresponding tendency for an enlargement of the scope of values among the disabled persons, evidenced by higher attainment ratings of any other life areas, was more difficult to find. This could be a true picture of the situation of living with a disability, although reports indicating the opposite also exist. For example, in a study of patients with rheumatic arthritis (15) it was found that as many as 70% agreed that their illness had opened their eyes to new possibilities in life. It should be noted, however, that the subjects in the latter study probably compared their present situation with some former situation of their own, such as when their illness was newly diagnosed and the consequences were perceived as more devastating. This points to the importance of carrying through longitudinal studies to examine more fully how life values change over time and in relation to changes in functional status and perceived quality of life.

No significant relations were found between attainment ratings and disease duration except for *mobility*,

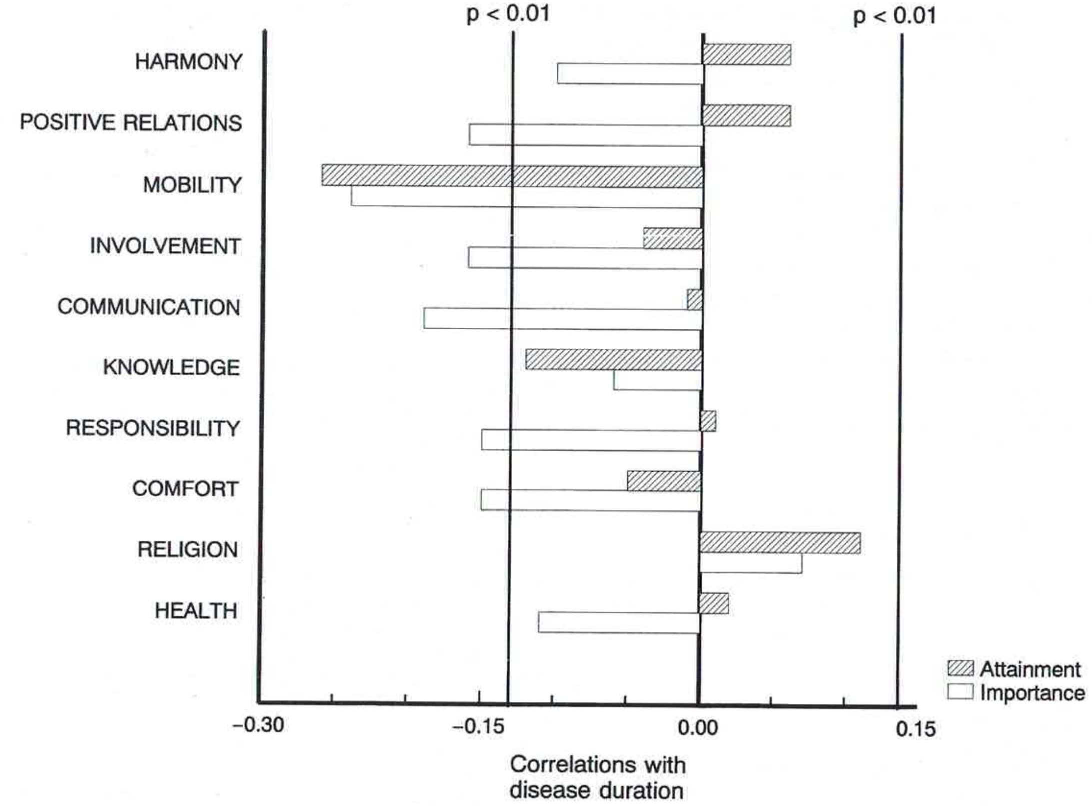

Fig. 3. Correlations between self-reported duration of the disability and attainment and importance ratings.

despite the fact that many diagnoses represented in the disabled group tend to become progressively worse. This suggests that the disabled persons tend to habituate to many of the effects of the the progression of their functional deficits.

Despite their obvious losses the mood level in the disabled group was only slightly lower than that of the control group. Although the difference was significant it corresponded to less then 6% of the scale range in the mood adjective checklist. The mood level of the disabled group in the present study was also quite similar to other disabled and/or chronically ill groups (rheumatoid arthritis, spinal-cord injured and severe pulmonary disease) tested by the same scale (15, 11, 8).

Our data on value orientations of disabled persons and the control group appear to agree quite well with those of Stensman's (19) on how mobility-disabled persons and non-disabled persons rank-ordered different "functions" (e.g. Love and be loved, See, Hear, Inner harmony). In both studies disabled and non-disabled persons largely agreed about the importance of different life values or functions. Sixteen of the 30 functions in Stensman's study were directly comparable to specific life values in the present study. The correlation between the ranks of these functions/values for disabled and non-disabled persons was 0.85 in Stensman's study and 0.84 in the present study. Moreover, in both studies the disabled persons tended to de-emphasize functions related to health and mobility.

The existential shifts of life orientation studied here are important aspects of coping in cases of chronic illness and/or disability, often mentioned in qualitative studies. Despite this, there are few empirical studies that have tried to examine the role of value shifts for well-being under these circumstances, and more specifically which types of life values may change and to what extent. Thus, in order to understand further how disabled people come to accept their irrevocable losses, the value-reorientation explored in the present study, should be an important topic for future research concerning coping. The present data suggest that disabled persons may cope with their new life situation by de-emphasizing the importance of lost benefits (particularly physical abilities which have been affected by the disability), and through habituation.

The described tendencies to de-emphasize and habituate to the lost benefits among disabled persons also have relevance for rehabilitation work. A reason why some patients drop out from or refuse to join rehabilitation programmes may not necessarily reflect that the patients have resigned or given themselves up to their disability, but that they have gradually adapted to the impairments and simply find it less important to continue struggling against the shortcomings.

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