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### Neuromuscular Diseases in the Context of Psychology and Educational Science

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#### 1. Introduction

In this chapter, neuromuscular diseases will be examined from both a psychological and an educational science perspective. Neuromuscular diseases are usually accompanied by many types of psychological strain as functional loss due to immobility or pain often corresponds to emotional impairment, such as fear or depression. The restrictions caused by the disease often remain life-long because as far as current knowledge is concerned no cure has been found yet. Patients' experiences have an immediate impact on both their beliefs about whether and how they can influence the course of their disease, and on their individual perception of their quality of life (Lohaus & Schmitt, 1989). A series of experiments showed that health-related control beliefs and individual quality of life of persons suffering from a serious chronic disease can be lower than of healthy persons (Benassi et al., 1988; Kleftaras, 1997). However, there are hardly any empirical findings pertaining to the area of neuromuscular diseases to this effect. Nevertheless, we may presume that health-related control beliefs and individual quality of life differ between patients with neuromuscular diseases and healthy persons. The following will summarize the findings from two studies, examining the extent of how persons with different neuromuscular diseases differ from healthy persons regarding their evaluation of their individual quality of life and healthrelated control beliefs.

Poverty reports and reports on the correlation between the social situation of people and their health agree that persons with a lower level of education (usually parameterized via the type of graduation achieved) often show a particularly poor state of health, or that they are sicker or die earlier than persons with a higher level of education (Altgeld & Hofrichter, 2000; Jungbauer-Gans & Kriwy, 2003; Richter, 2005; Lambert & Ziese, 2005; Robert Koch Institut & Bundeszentrale für gesundheitliche Aufklärung, 2008). Both health sciences and health politics agree that education by imparting knowledge and promotion of individual disposition and talent support the development of health in childhood and adolescence, and also corresponds to better health in adulthood (Lambert & Ziese, 2005).

Almost all epidemiological studies report on social inequality in the sense of unequal access to life opportunities and life risks. Furthermore, data on individual educational biography is

being gathered in almost all international health surveys. Many of the social differences not only map different living conditions, but also result in tangible advantages and disadvantages among the individual members of society (Richter, 2005). Especially during the past two decades, a vast number of publications have shown that a low socio-economic status (defined as a low degree of educational achievement, low-level job, and/or low income) is accompanied by an increased degree of mortality and morbidity (Mielck, 2000). This applies to children, adolescents, adults, men, and women alike.

Why the mortality of someone who has a low income or a low degree of educational achievement, respectively, but who does not have to starve or freeze is higher than the mortality of someone with a higher income or educational level does not seem to be obvious when only seen at a glance. Education, occupational status, and income continue to influence the state of health only indirectly and are transferred with factors associated with social status. The large number of health-relevant living conditions and behaviors makes a complete explanation of status-specific differences in morbidity and mortality almost impossible (Mielck & Helmert, 2006). To date, the focus of scientific discourse has been on the unsolved causal chain of the socio-economic status affecting the state of health and the state of health in turn influencing the socio-economic status (Mielck & Helmert, 2006). The question of the extent to which both may be confounded by a third variable complicates the causal approach even more.

Findings on educational differences in respect of disease frequency and health-related behavior are reported in particular by the Robert Koch Institute (2006) within the framework of a telephone survey on health. Heart attacks, angina pectoris, arthrosis, chronic back pain, and dizziness in men are related to a low educational level. In women, the educational level is related to hypertension, diabetes mellitus type 2, and chronic bronchitis (Lambert & Ziese, 2005). Furthermore, educational differences also become evident in health-related behavior (smoking prevalence, physical activity, etc.), the distribution of overweight and obesity, as well as the usage of information sources referring to health-related topics. It needs to be noted that in this context, the term "education" is often used unidimensionally and current definitions from the area of educational science are neglected.

#### 2. Health-related quality of life in the context of education

#### 2.1 Theoretical approach – Definition

Health-related quality of life is a multidimensional construct that has so far managed to escape a clear definition, which explains why the term is extended, always depending on the definition criteria (Daig & Lehmann, 2007). Another difficulty is finding plausible criteria for a distinct, empirical validation. In principle, this context leads to the question to what extent criteria can be used for explaining the term, with the help of which it is possible to reflect and describe the general state of health regardless of existing diseases, or, on the other hand, whether it would not be preferable to rather base the explanation of the term on disease-specific criteria. With the latter, health would be defined as the degree of disease that allows an individual to perform actions that the individual wants to perform.

Despite the problems described it seems possible to close in to the construct from different perspectives. For example, the WHO sees quality of life as "an individual's perception of

his/her position in life in 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, mental state, level of independence, social relationships, and their relationship to salient features of their environment" (WHOQOL-Group, 1994, p. 43). The term also includes personal targets, expectations, criteria, and concerns. People are, however, faced with a number of influencing factors: For example, physical health, mental state, social relationships, as well as personal beliefs influence an individual's quality of life (Radoschewski, 2000). The term quality of life is, at the same time, closely connected with happiness, content, and well-being, often even used as synonyms (Daig & Lehmann, 2007).

Health-related quality of life is viewed in the context of the state of health and ability to act of people who suffer from disease or are chronically ill (Bullinger et al., 2000). According to Schumacher et al. (2003), primarily four dimensions play a determining role:

- 1. disease-related physical discomfort,
- 2. mental state,
- 3. disease-related functional restrictions in daily life,
- 4. quality of social contacts.

Health-related quality of life is a result of many individual, complex evaluation and assessment processes that, in turn, all need to be analyzed based on many dimensions, as well (Daig & Lehmann, 2007). They include, for example, emotional well-being, together with a feeling of security, a stable and predictable environment, positive feedback by others, as well as interpersonal relationships, which means that one feels accepted in a community and works regularly. Moreover, personal development in terms of education, targeted activities, and physical well-being defined by health care, mobility, a sense of wellness, and a healthy diet, play an essential role. Not to be neglected in this context are self-determination, social integration, the right of privacy, and property.

#### 2.2 Quality of life within the framework of neuromuscular diseases

Quality of life comprises the emotional, social, mental, and functional areas of human life (Bullinger & Pöppel, 1988). It cannot be observed from the outside but can only be indirectly derived from various aspects. These aspects mainly include a person's physical well-being, functional capabilities and performance in various areas of life, the number and quality of relationships with other human beings, and physical shape. Especially with long-time chronic diseases, individual quality of life is very important for the patients. Considering all this is essential for the patients' dignity during medical treatment, which particularly applies to long-term treatment and care. Since an evaluation of quality of life is unreliable and variable due to disease, treatment, and impairments it is probably best assessed by patients themselves (Helmchen, 1990). In practice, quality of life is rather still determined by doctors' diagnoses and not by the patients themselves. A number of studies show, however, that there can be significant differences between these two evaluations. When recording quality of life, the postulate of the subject reference of the measurement of quality of life should be taken into account, and indicators of personal and social resources should be integrated in the measurement (Siegrist, 1990).

With neuromuscular disease, functional loss caused by pain or immobility are often so serious that individual quality of life strongly depends on the way the patients cope with and handle their state. To maintain and enforce required lifestyle changes, such as participating in specific movement programs (Koch & Burgunder, 2002), self-regulating mechanisms and support from the social environment (e.g., family, friends, other ill persons, etc.) are decisive factors. In the course of neuromuscular diseases, personal and social resources play a special role in the development and impact of the disease (Koch & Burgunder, 2002).

Interestingly, studies show that compared to a healthy group of persons, patients with chronic, impairing, and progressive diseases express comparable or even better assessments of their subjective quality of life. This phenomenon is usually called the "well-being paradox" or "satisfaction paradox", or adaptation. It means that difficult living conditions do not necessarily have to result in poorer assessments of subjective well-being or quality of life (Daig & Lehmann, 2007). Robbins et al. (2001) showed that the assessment of the quality of life of patients with ALS does not primarily depend on the physical state of health. In a study by Lulé et al. (2008), the average subjective quality of life of ALS patients was 66-72 % and thus in an area that is comparable with healthy control persons. Similar results regarding the fact that many chronically ill people feel "quite well actually" are reported by Raspe (1990). He is of the opinion that ill people obviously differentiate between perception and description of complaints and an evaluation of their overall situation. Even if somatic manifestations of disease and complaints have already led to disorders in the mental and social balance, it is apparent that the afflicted persons do not inevitably connect each disorder with dissatisfaction and negative evaluations. Being ill usually affects the performance and reliability of the body. Physical ability is therefore an important, but not an exclusive component of quality of life. Quality of life indicators are criterion variables that can change in the short and medium term depending on disease characteristics and therapy (Siegrist, 1990). For instance, Diehl et al. (1990) were able to show during their examinations involving tumor patients that the disease brought to light variation and maturing opportunities that had so far been unknown to the persons. They discovered new meanings and values, particularly regarding their relationships with other persons, expectations of life, and their newly obtained ability to set priorities and distinguish between the important and unimportant. This all means that the risk of a possibly drastically reduced lifetime seems to shift life-related preferences.

It has long been known that the educational background of a person corresponds to the subjective assessment of health and disease aspects (Boltanski, 1976). In patients with ALS, Lulé et al. (2008) discovered confounding variables in terms of education and depressive symptomatology: the higher the degree of education, the lower the depression value. Based on these findings, the first study was to elicit the extent to which persons with various neuromuscular diseases differ from healthy persons in their assessment of overall quality of life, and to what extent education is influencing this aspect.

#### 2.3 Study 1 – Quality of life and education in the context of neuromuscular diseases

#### 2.3.1 Methodology

For this study, data of 178 persons was collected. The experimental group comprised 96 persons, 37 men and 59 women with an average age of 50.02 years (SD = 13.22 years). The

most frequent disease patterns were muscular dystrophy (22.9 %), muscular atrophy (9.3 %), and ALS (6.2 %). The control group consisted of 82 persons who did not suffer from either neuromuscular or other chronic diseases. This group comprised 37 men and 45 women with an average of 38.67 years (SD = 11.05). The distribution between the sexes did not show any significant differences ( $\chi^2 = 0.79$ ; df = 1; Cramérs V = 0.07). The persons with neuromuscular diseases exhibited a significantly higher age than the control group (F = 37.84; df = 1; p < 0.05;  $\eta = 0.42$ ). In terms of education, the test persons were divided into the categories "without advanced technical college entrance qualification" and "with advanced technical college entrance qualification". A significant difference became evident insofar as the persons of the control group had a higher educational level ( $\chi^2 = 14.81$ ; df = 3; p = 0.05; Cramérs V = 0.29).

The general overall quality of life was surveyed using the EUROHIS-QOL 8 Item Index questionnaire (Brähler et al., 2007). Within the scope of this survey tool, the psychological, physical, social, and environmental dimensions of the quality of life are recorded based on two items each see Table 1. The index value is calculated by adding the 8-item scale values. The higher the value, the better the quality of life was estimated (Brähler et al., 2007). The individual items are to be answered using a five-step format ("Does not apply at all" to "Applies completely").

Item	Subscale	Factor
How would you rate your quality of life?	Psychological	Endogenous
How satisfied are you with your health?	Psychological	Endogenous
Do you have enough energy for everyday life?	Physiological	Endogenous
How satisfied are you with your ability to perform your daily activities?	Physiological	Endogenous
How satisfied are you with yourself?	Social	Endogenous
How satisfied are you with your personal relationships?	Social	Endogenous
Have you enough money to meet your needs?	Environment	Exogenous
How satisfied are you with the conditions of your living place?	Environment	Exogenous

Table 1. Items of the EUROHIS-QOL 8 Item Index

In addition to the general descriptive methods, such as averages and standard deviations, the inferential statistics check was performed in dependence of the scale level with the corresponding tests for difference checks. The prognostic potential was done via  $\eta$  or  $\eta^2$ , respectively. For internal consistency revision of the items, Cronbach's  $\alpha$  was calculated. The significance level was set to p < 0.05.

#### 2.3.2 Results and discussion

The overall index (sum of four subscales) as a value for general overall quality of life showed a major difference (F = 36.80; df = 1; p < 0.05;  $\eta^2$  = 0.18) between the experimental group (26.95 ± 6.02) and the control group (31.68 ± 4.25) in the linear model based on the factors Group (neuromuscular disease vs. no neuromuscular and chronic disease) and

Education (without advanced technical college entrance qualification vs. with advanced technical college entrance qualification or university entrance qualification), as well as the covariate Age. The interaction of Group by Education did not result in any significant differences (F = 3.16; df = 1; p = 0.08;  $\eta^2 = 0.02$ ). When analyzing the individual subscales, major effects became evident in the following dimensions:

Subscale	Experimental group	Control group
Psychological	$5.82 \pm 1.68$	7.72 ± 1.42
Physiological	6.21 ± 2.06	7.87 ± 1.37
Social	$7.18 \pm 1.84$	7.99 ± 1.26
Environment	7.51 ± 2.12	7.91 ± 1.76

Table 2. Significant main effects of subscales (all p < 0.05)

Moreover, the physiological subscale showed a significant interaction of Group and Education (F = 8.00; df = 1; p < 0.05;  $\eta^2$  = 0.05). Summing up these findings, it is safe to state that persons not suffering from neuromuscular diseases report a higher degree of satisfaction with life than ill persons (Fröhlich et al., 2009). This difference is evident both from the overall index as well as the questionnaire's subscales. Since the age of the persons surveyed can influence the result it was taken into account as a covariate. The analysis of the level of education influencing the satisfaction with life did not show any major connection between education and assessment of the quality of life. This also applies if the persons suffering from neuromuscular diseases and having a higher degree of education degree of education report on the general overall quality of life. In contrast to the findings of Robbins et al. (2001), Lulé et al. (2008), and Raspe (1990), the assessment of overall quality of life within the scope of this survey of persons having a neuromuscular disease is lower than in a comparison sample with persons not suffering from neuromuscular or other chronic diseases.

#### 3. Health-related quality of life in the context of education

#### 3.1 Theoretical approach – Definition

In line with the construct of control beliefs, persons expect to be able to positively influence or control their own health-related behavior (Lohaus, 1992; Petermann & Roth, 2006). This construct is based on the social learning theory by Rotter (1966) and the *locus of control of reinforcement* concept used therein. The center of the concept is that people assume that they can influence events in their life (Krampen, 1988; Ferring & Filipp, 1989). This particularly applies to how they presume that their own state of health may be influenced by their own or other people's actions (e.g. doctors, physical therapists) or even by fate. Other theories related to the concept refer to the model of learned helplessness by Seligman (1975), the cognitive depression model by Beck (1972), and the self-efficacy theory by Bandura (1977).

According to Filipp and Mayer (2005), to perceive oneself as competent and be convinced of the efficacy of one's actions is fundamental human pursuit, which can already be observed in the first year of one's life. The belief to be able to influence and control one's health is usually based on previous knowledge about effects that individuals have learned of during

their development, and on the experiences made concerning self-determination and heteronomy in the areas of physical and health-related processes (retrospective behavioral plasticity). Accordingly, control beliefs in this area are understood as the generalized results of previous learning experience (Lohaus & Schmitt, 1989), which are accompanied by divergences if previous knowledge and experiences exist for different forms of disease, which can lead to different expectations of the diseases' controllability.

If persons believe that their actions can lead to or influence specific events they have what is called an internal control belief. If persons think they are not able to bring about certain events through their own actions but are instead convinced that other people's actions or even luck or fate are the cause of events, these persons are said to have social-external or fatalistic-external control beliefs (Levenson, 1972, 1974). In this context, internal control beliefs are evaluated as a personality resource for mental well-being and for coping with health-related issues (Krampen, 1988). Faith in the influence of medical staff (social-internal) can stabilize the patients' well-being if they depend on medical help (Taylor, 1999). Fatalism, however, is deemed dysfunctional for psychological adaptation (Krampen, 1988). Here, aspects of independent and interdependent self-construction come to play an important role, i.e., to what extent persons experience themselves as actively planning and self-determined (Pieter et al., 2010), or to what extent persons define themselves via the association with other persons (Hannover & Kühnen, 2002).

The scope of subjective perception of control options correlates to thinking, feeling, and acting. Often, a low control belief is directly related to depression, anxiety, and low self-esteem (Bandura, 1993, Resetka et al., 1996). Positive control beliefs, however, are accompanied by optimism. Difficult tasks are considered as individual challenges (Caraway et al., 2003; Hintze & Shapiro, 1999). Persons with a high control belief show a higher degree of stamina and recover faster from setbacks when faced with difficult and unpleasant tasks (Bandura, 1999; Jerusalem & Mittag, 1999; Määta et al., 2002). Positive control beliefs are pointed out as predictors or correlates of the ability to handle stress and mental and physical health in a large number of empirical surveys (Flammer, 1990; Kuhl, 2001; Schwarzer & Fuchs, 1996). A subjectively deemed low controllability of the disease can lead to reduced ability to act according to Biebrich and Kuhl (2004). If persons feel helplessly subjected to the disease they can hardly demonstrate intact control during the hard-to-control phases of the disease's development.

A number of studies report that health-related control beliefs cannot be explained exclusively based on the condition of persons and that the connection of health-related control beliefs is moderated beyond the current condition by other variables (summarizing, see Fröhlich et al., 2007). In this context it was shown that a low educational level and/or low income are accompanied more by lower and fatalistic-external control beliefs and less reverting to own capabilities (Ross & Sastry, 1999). Since control beliefs not only depend on existing diseases and complaints, but also on health-related attitudes, perceptions, and comparisons – on the one hand concerning the individual course of the disease and on the other concerning the social reference group – educational differences can have particularly serious effects. The general question arises whether a stronger development of control beliefs is influenced by the educational level, or if the general condition or current state of health has a stronger influence on the subjective control beliefs on health and disease.

#### 3.2 Control beliefs within the framework of neuromuscular diseases

Neuromuscular diseases usually bring many handicaps for the affected, such as physical damage, restricted functionality and activity, and general performance limitations in daily life. These restrictions often correspond to emotional burden, such as fears, depression, low self-esteem, and the endangerment of professional and social participation and integration. The majority of patients must change their lifestyle to adapt to the disease genesis. They must undergo frequent diagnostic examinations, continue to take their medication, and possibly even make use of stationary therapy. The restrictions often remain life-long because as far as current knowledge is concerned no cure has been found yet (Fröhlich et al., 2010; Pieter et al., 2011).

To date, a series of examinations has shown that health-related control beliefs in persons suffering from a major chronic disease can be less than in healthy persons. Krampen (1988), for example, found that depressive patients exhibited a reduced self-concept of their own ability and internality as well as a socially induced externality and significantly increased fatalistic externality. A connection between reduced internal control beliefs and increased fatalistic externality with depressive moods has also been proved in numerous studies (Burger, 1984; Benassi et al., 1988; Kleftaras, 1997; Weinmann et al., 2001). The question whether these control beliefs cause a depressive mood or whether the depressive mood causes the control beliefs remains unanswered at this point.

As stated above, control beliefs associated with health and disease are mostly based on previous knowledge about effects on health and disease, which individuals have attained in the course of their lives, and on the experiences made concerning self-determination and heteronomy in the area of physical processes (Lohaus & Schmitt, 1989). It is an obvious assumption that control beliefs differ between healthy and ill persons. Particularly with diseases occurring multiple times or over a long time, learning experience regarding individual control options (both internal and external control) is likely to exist. Based on these assumptions, the control beliefs of both persons suffering from neuromuscular diseases and healthy persons will be examined and compared in the second study.

#### 3.3 Study 2 – Control beliefs and education in the context of neuromuscular diseases

#### 3.3.1 Methodology

The overall sample of this study consisted of 176 persons (41.2 % men and 58.8 % women) with an average age of 44.67 years (SD = 13.42). The experimental group comprised 94 persons (38.5 % men and 61.5 % women) suffering from a neuromuscular disease diagnosed by a doctor. The average age of this partial sample was 50.02 years (SD = 13.22). The control group represents a random sample of 82 persons who were recruited through direct contact. Precondition for being assigned to this group was, as in Study 1, that the persons had not been diagnosed with neither neuromuscular nor other chronic diseases. These test persons had an average age of 38.32 years (SD = 10.65) and were 45.1 % men and 54.9 % women.

The test persons were asked to evaluate their current general state of health based on a seven-level Likert scale (1 = "very poor" to 7 = "very well") (as to the reliability of this method, please refer to Ravens-Sieberer et al., 2000; Gunzelmann et al., 2006). Persons without neuromuscular disease set their state of health at an average of 5.78 (SD = 0.91), the

ones with neuromuscular diseases at 3.74 (SD = 1.26). Their evaluations differed significantly (F = 111.88; df = 1; p < 0.05;  $\eta_p^2 = 0.40$ ). In the control group, one person evaluated themselves as currently not healthy at all, 7 persons experienced themselves as partly healthy, and 78 persons felt completely healthy. In contrast, 38 persons of the experimental group considered themselves as absolutely unhealthy at the point of the survey, 30 persons felt partly healthy, and 20 persons felt completely healthy despite their neuromuscular disease.

Degree of education	Overall sample (N = 176)	Experimental group (N = 94)	Control group (N = 82)
Without advanced technical college/university entrance qualification	73 (41.5 %)	51 (54.2 %)	22 (26.8 %)
With advanced technical college/university entrance qualification	103 (58.5 %)	43 (45.8 %)	60 (73.2 %)

Table 3. Educational level of test persons from Study 2

The questionnaire developed by Lohaus and Schmitt (1989) on recording control beliefs about disease and health was used as a survey tool. The questionnaire includes three subscales that correspond to the control belief dimensions "internality", "social externality", and "fatalistic externality". All items of the measurement tool are formulated as statements that the test participants can process based on a six-level scale. From their answers, a score is calculated that expresses the control belief in the three subscales. All items avoid the terms "health" and "disease", rather pointing to physical states that both healthy and ill persons are familiar with. Lohaus and Schmitt (1989) postulate that therefore, both healthy and ill persons can process the items in the same manner. For statistical review, absolute and percentage frequencies were calculated in addition to average values and standard deviations. To meet the requirement of sufficient cell frequency, the educational level was categorized into the group of test persons with certificate of secondary education/general school-leaving certificate and in the group of test persons with advanced technical college/university entrance qualification. Furthermore, using the median and identical category ranges, the current general state of health was divided into very ill persons, partly healthy, and completely healthy persons. Due to the low degree of cell frequency in the control group (see remarks on sample) this group is not considered in the calculations of the current general state of health.

For the inferential statistics check, variance-analytical procedures were calculated after verifying the corresponding preconditions. To estimate the effect size, eta squared ( $\eta^2$ ) or partial eta squared ( $\eta_p^2$ ), respectively, were applied. Values for ANOVA calculations of 0.1 and 0.24 are to be viewed as small effects, values of 0.25 and 0.39 as medium, and above 0.4 as large effects (Bortz & Döring 2006). Since there are major differences in the two groups in terms of age (F = 40.97; df = 1; p < 0.05;  $\eta_p^2$  = 0.19), the age was taken into account in all calculations as a covariate. The level of significance was p < 0.05.

#### 3.3.2 Results and discussion

In the internality subscale, persons with neuromuscular diseases and healthy persons differ significantly (F = 9.91; df = 1; p = 0.02;  $\eta_p^2 = 0.06$ ). The following table illustrates the relevant average values and standard deviations:

	Without advanced technical college/university entrance qualification	With advanced technical college/university entrance qualification
Experimental group	28.22 ± 7.12	$25.44 \pm 7.54$
Control group	22.85 ± 7.81	$20.93 \pm 5.64$

Table 4. Average values and standard deviations for the internality subscale

Concerning the educational level (without advanced technical college/university entrance qualification vs. with advanced technical college/university entrance) no significant differences (F = 1.10; df = 1; p = 0.30) were founded. However, for persons with neuromuscular disease, this subscale exhibited a significant difference (F = 6.55; df = 2; p = 0.02;  $\eta_p^2 = 0.13$ ) between very ill persons and completely healthy persons (p < 0.05), as well as between partly healthy and completely healthy persons (p < 0.05).

In the social externality subscale, neither group differences (F = 1.61, df = 1; p = 0.21) nor educational differences (F = 1.51; df = 1; p = 0.22) were evident. With persons with neuromuscular disease, no significant differences (F = 2.64; df = 2; p = 0.08) were evident concerning the evaluation of the general state of health. When observing the fatalistic externality subscale, there are no group differences between ill and healthy persons (F = 1.08; df = 1; p = 0.30). However, in terms of education, significant differences between persons without advanced technical college/university entrance qualification and persons with advanced technical college/university entrance qualification came to light (F = 4.50; df = 1; p = 0.04;  $\eta_p^2$  = 0.03). The average values and standard deviations are illustrated in the following table:

	Without advanced technical college/university entrance qualification	With advanced technical college/university entrance qualification
Experimental group	29.91 ± 8.25	33.15 ± 6.95
Control group	32.15 ± 5.81	35.25 ± 4.37

Table 5. Average values and standard deviations for the fatalistic externality subscale

For persons with neuromuscular disease, a significant difference (F = 4.20; df = 2; p = 0.02;  $\eta_p^2$  = 0.09) is shown in this subscale between completely ill and partly healthy persons (p < 0.05).

Persons suffering from neuromuscular diseases are obviously more convinced than healthy persons that their own activities and actions positively influence the course of their disease, which enables them to better cope with health-related burdens. Regarding their health, they experience themselves as actively planning and acting in a self-determined way. All this is evidence for optimism in this group and the conviction that difficult tasks represent a

challenge and can be solved. In all, this finding is in favor of the mental health of the examined persons with neuromuscular somatic disease. The lower values in the group of healthy persons could be based on the fact that previous knowledge and experience with severe diseases are lacking or only very rare and thus lead to different expectations of the individual scope of actions than is the case with ill persons. Ill persons seem to be able to anticipate and assess the future impact of their own behavior based on their existing experience with diseases. In contrast, healthy persons can align their behavior only with mentally represented states of disease (Goschke, 2004).

Even if persons with neuromuscular diseases are objectively seen ill they still estimate their current general state of health as rather well. A large number of the persons surveyed even feel completely healthy. When looking at the diagnoses of these persons with a view to their subjective control beliefs it becomes evident that the three subgroups differ significantly in their internality. Those persons who assessed themselves as partly healthy at the time of the survey have the highest degree of internality, followed by the completely ill and the completely healthy. The diagnoses in these cases again speak for a learning effect or, respectively, can be interpreted as a clue that the terms health and sickness are indeed social constructs. Considerably more partly healthy persons than completely sick persons consider luck and coincidence to be strongly influencing their disease, i.e. completely sick persons will more likely actively fight their disease using their own means or asking others for help.

With respect to education, there was only a significant difference when it came to fatalistic externality. Persons with a higher level of education (with advanced technical college/university entrance qualification) are more convinced that health and sickness depend on coincidence and fate. This conviction, however, can turn out to be dysfunctional for psychological adaptation within the framework of coping with a disease. This seems to be strange to the group of those with a higher level of education and contradicts the findings of Ross and Sastry (1999). At first glance, the result is surprising and requires more detailed verification in further surveys. At large, however, the low effect size and the fact that the test persons of the experimental group generally have a lower level of education need to be considered here, as well (Fröhlich & Pieter, 2009).

#### 4. Conclusion

Persons suffering from neuromuscular diseases are more convinced than healthy persons that their own activities and actions positively influence the course of their disease. They use this personality resource to a higher degree, which enables them to better cope with their personal health-related problems. They experience themselves as actively planning and selfdetermined with respect to their health. This is evidence of optimism in this group and the conviction that difficult tasks represent a challenge and can be solved. Overall, these findings all points toward the mental health of the persons examined here with a neuromuscular somatic disease. The lower values of the healthy persons may result from their lack of or very little previous knowledge and experience with severe diseases and that they therefore have different expectations of their individual ability to act than ill persons. Ill persons seem to be able to anticipate and assess the future impact of their own behavior based on their existing experience with diseases. In contrast, healthy persons can align their behavior only with mentally represented states of disease (effect anticipation and determination sensu Goschke 2004). The anticipation is thus directly associated with the individual learning history of the person. Therefore, it seems easier for persons with neuromuscular disease to establish preventive goals that are not based on the current needs, but rather geared to the satisfaction of future requirements. This type of suppression of current needs in favor of future needs requires a certain measure of willpower in an individual (cf. Goschke, 2004; Pieter et al., 2010).

Even if persons with neuromuscular diseases are objectively seen ill they still estimate their current general state of health as rather well. A large number of the persons surveyed even feel completely healthy. Considerably more partly healthy persons than completely sick persons consider luck and coincidence to be strongly influencing their disease, i.e. completely sick persons will more likely actively fight their disease using their own means or asking others for help.

With respect to education, there was only a significant difference when it came to fatalistic externality. Persons with a higher level of education (with advanced technical college/university entrance qualification) are more convinced that health and sickness depend on coincidence and fate. This means that these persons turn out to be less persistent in difficult and uncomfortable health-related situations, that their ability to act is reduced and that they process setbacks slower. This may be explained by an inability to anticipate and assess the future impact of their behavior. Being convinced of the fact that a disease depends on coincidence and fate is accompanied by the feeling of being helplessly exposed to the disease. According to Tausch (2008), feelings such as helplessness or powerlessness are further promoted by not understanding external processes and subsequently recognizing pointlessness.

In addition to the fact that it is difficult to compare educational levels within age groups, it is also difficult to suitably record education and learning processes in general (Reinmann, 2010). Therefore, the question arises whether the operationalization of the construct of education (in the sense of educational level achieved) selected in this context may not be sufficiently exhaustive as an explanatory variable in the context of health, and whether education as a health resource should rather be a combination of many more factors than mere education in the sense of educational level achieved. In this context, an operationalization of education via competence seems to be more plausible even though a definition of the term is difficult because it has multiple connotations in both informal and scientific speech (Hartig, 2009). In educational research, the comprehension of competences as learnable, context-specific cognitive performance dispositions has been proven (Hartig, 2009). In health research, they should also include motivational orientations, attitudes, tendencies, and expectations sensu Weinert (1999). Instead of operationalizing general education via school education, an approach taken from positive psychology (see Seligman, 2010) and the resulting deliberations on the meaning of the so-called "wisdom competences" seem to be more productive in the area of health (see also Baumann & Linden, 2008) and more suitable in connection with coping with the stresses of life. When considering the assumptions by Erikson (1976) about the central development task in adolescence being to master one's one life and fate, this presumes a certain degree of "mature thinking" in an individual (Baumann & Linden, 2008, p. 32). This mature thinking can be described as relativizing, dialectic, complementary, and closely corresponding with learning processes, but not necessarily with the level of education achieved. In its highest form, this type of

thinking is called "wisdom" in psychological development research (Baltes & Smith, 1990; Staudinger & Baltes, 1996), represents - according to current knowledge - an important resource in terms of positively coping with critical life events (Baumann & Linden, 2008), and could therefore be utilized in health research. In this context, wisdom can be defined as skill or expertise in a specific context, with the thoughts on this being based on philosophic, implicit, and explicit wisdom theories (for an overview, see Baumann & Linden, 2008). From these theories, a ten-dimensional model of wisdom competencies has been derived, comprising cognitive, emotional, and motivational competencies. Furthermore, it is to analyze what are the differences between the neuromuscular disorders and other chronic disorders causing disability in the context of psychology and educational science and what are the effects of the therapy of different neuromuscular disorders in this context. The low degrees of cell frequency in the present studies not allow these conclusions. Further studies could shed a more detailed light on this area of research.

#### 5. Summary

It was examined to what extent persons with various neuromuscular diseases differ in terms of their evaluation of their individual quality of life and health-related control beliefs in from a comparison sample. As expected, healthy persons reported a higher degree of satisfaction with life. In contrast, persons with neuromuscular disease display a higher degree of internal and a lower degree of fatalistic control beliefs.

According to these findings, education is ascribed only a limited, explanatory value in association with health-related control beliefs. It is recommended that further studies extend the concept of education to include health sciences based on current findings from educational research. One option is a diagnostic on wisdom competencies carried out using established measurement methodology and linked with health-specific knowledge, skills, and strategies.

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