

Role of Personal Strivings in the Community Integration of Individuals with NMD

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Personal strivings describes a model of community integration that is based on personal goals. These goals are what a person is characteristically trying to do or be and they provide access to what he/she is potentially capable of becoming. This framing of subjective quality of life outcomes such as personal well being in terms of goals leads to new possibilities for understanding adaptation to physical disabilities and offers substantial advantages for addressing the psychosocial needs of persons with disabilities and for ultimately improving the quality of their lives.

Asking each person directly what he/she wants out of life assists in identifying current priorities and commitments; precisely where they are in terms of functional abilities, current perceptions of their overall quality of life, and their concerns for the future. This direct personal input gives each person with a disability a voice in examining what he/she wants out of life in various areas, including home, work, recreation, and relationships and it allows each person to set goals that are appropriate for his/her physical and emotional abilities or limitations at the time of goal setting. This framing of subjective quality of life outcomes in terms of goals leads to new possibilities for understanding adaptation to physical disabilities. It better equips each person to identify sources of frustration and futile effort, particularly when trying to meet the expectations of uninformed external individuals. Individuals with a high sense of well-being tend to pursue goals that are important and meaningful, moderately difficult and challenging, fueled by optimistic expectations, supported by others, and free from conflicts arising from competing goal concerns or interpersonal obstacles. Goals make life meaningful, valuable, and purposeful. They lie at the heart of what it means to live a life of quality; they are, therefore, central to quality of life research.

The outcome of setting goals for people with disabilities is the achievement of a realistic sense of what is both possible and desirable in terms of physical and emotional adaptation to disability and any limitations a disability may present. In doing so they are better equipped to identify sources of frustration and futile effort, particularly in trying to meet uninformed external expectations.

The purpose of this clinical study was to test the applicability of a goals-based model for the enhancement of community integration of persons with neuromuscular disorders. This approach offers substantial advantages in addressing the psychosocial needs of persons with disabilities to ultimately improve their quality of life. We hypothesized that there would be connections between personal goal systems and well-being in this sample of persons with NMD. Striving systems that are characterized by predominantly negative, avoidance strivings will be related to lower satisfaction ratings and a greater frequency of unpleasant emotions. Strivings that are perceived as highly valued, attainable, and provide meaning and purpose will be those that contribute most

strongly to a sense of well-being.

We utilized the Personal Strivings Assessment Packet to evaluate subjective well being rather than standard, questionnaire measures of community integration. Preliminary results showed that this goal-based method was the strongest predictor of overall levels of well being (life satisfaction, positive affect, and vitality) of any of the other goal variables examined. The strongest predictors of life satisfaction were community integration through goals, perceived meaningfulness of the goals, and low goal difficulty. In addition, a goal-based measure of spirituality (self-ratings of the degree to which the goal brings the person closer to God) was predictive of life satisfaction and positive emotionality. The degree to which pain interfered with the person's ability to work toward his/her goals was predictive of psychological distress (negative effect). However, a direct self-report of degree of pain recently experienced was unrelated to subjective well-being. Another predictor of a negative result from the goal setting was the amount of interpersonal strain caused by the striving. These results, taken as a whole, suggest that a goal-based approach to community integration is viable and invites further exploration into the role of personal goals as workable clinical units of analysis for understanding the quality of life in the lives of persons with neuromuscular disease. However, in this study little information has been provided as to what factors are critical to achieving a high quality of life. Facilitating the patient's identification of personally meaningful, attainable strivings and developing workable strategies for their accomplishment becomes a priority for rehabilitation providers.

In an additional study, the participants in the initial study were divided in thirds as listed:

- *quality of life intervention.* They kept daily records for 21 days recording their moods, health behaviors (sleep duration and quality, pain and pain interference with daily activities, exercise), difficulty in activities of daily living, positive life events (things for which they were grateful) and global ratings of life satisfaction, optimism for the upcoming day, and feelings of connectedness to others and wrote down up to 5 things in their lives for which they were grateful or thankful.
- indicated a person to whom they were grateful.
- control group who did no listing each day.

We found that the group with the quality of life intervention, when compared to the control group, experienced more high-energy positive moods (such as enthusiasm, alertness, and vitality), a greater sense of feeling connected to others, more optimistic ratings of one's life, and better sleep duration and quality. A number of the participants wrote to us expressing how valuable this daily monitoring procedure was for them, and how it led to an increased appreciation for the goodness in their lives. The transformative power of positive emotions has been documented in much recent research. Our participants report that such "magical" moments or periods of time, described by many as states of increased spiritual connectedness, were triggered by the genuine experience of heartfelt positive emotion. The experience of deep appreciation for another's kindness

increases the perception of connectedness to others and perhaps with all of humanity. Our research provides objective evidence of what we have long known intuitively, that positive emotional states may indeed be key to optimal functioning, enhancing nearly all spheres of human experience, including a sense of integration or connectedness.