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PSYCHOSOCIAL ADAPTATION TO DISABILITY AND ITS INVESTIGATION AMONG PERSONS WITH MULTIPLE SCLEROSIS

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Abstract—This review begins with a general discussion of the concept of psychosocial adaptation to disability, reaction phases that the adaptation process is thought to comprise, instruments to measure adaptation and the basic research questions that need to be addressed to construct a theoretical model for the process. The research literature concerning psychosocial adaptation to disability among persons with multiple sclerosis is reviewed as an illustration. Research problems identified in this review are then listed, with suggestions for future research.

Key words—psychosocial adaptation, reactions, disability, multiple sclerosis

INTRODUCTION

The literature on psychosocial adaptation to disability [1–8] contains valuable theoretical discussions and the results of clinical studies with diverse populations. Examination of this literature shows, however, there is little agreement on the nature of the concept. Several authors [9–11] view psychosocial adaptation to disability as one of a set of independent and non-sequential patterns of human behavior. Most authors [12–15] have posited models in which adaptation is conceptualized as a process of change in reactions triggered by functional limitations associated with external environmental antecedents (e.g. accidents, trauma) or internal pathogenic conditions (e.g. diseases). From a methodological perspective, the adaptation process suggests an unfolding paradigm in which reactions can be temporally and hierarchically ordered.

Frank *et al.* [3] made a distinction between 'phase' and 'stage' theories. They view phase theories as those that describe loosely organized, nonexclusive psychological changes that may partly overlap each other. Stage theories, on the other hand, are those that describe discrete and mutually exclusive psychological processes. A person, according to this theory, can be in only one stage at a particular time. In this paper we will adopt the phase terminology and refer to the specific behavioral manifestations of a phase as reactions.

Constructing a model for the process of psychosocial adaptation to disability entails observation and measurement of the ways that persons with disabilities perceive, assess, cope with, and gradually assimilate various changes in body, self and person-environment interactions necessitated by their impairments. These data would yield answers to such questions as: Is the process of psychosocial adaptation to disability unidimensional or is it composed of discernible phases that can be reliably measured? Is there a universal set of phases that characterize this process? Are the phases uniform across various types of impairment or are they impairment-specific? Can the phases be ordered temporally and hierarchically? Is the order linear? What characteristics (e.g. demographic, impairment-related, situational) are associated with inter- and intra-individual variability in adaptation?

PSYCHOSOCIAL ADAPTATION TO DISABILITY

Reaction phases

Reviews of research concerning psychosocial adaptation to disability [16–20] most often discuss the reaction phases of shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgment and final adjustment.

Shock is perceived as the person's initial reaction to the onset of a sudden and severe physical impairment (e.g. spinal cord injury, myocardial infarction) or psychological trauma (e.g. diagnosis of a chronic disease, death of a loved one). It is a reaction noted by a psychic numbness resulting from the impact of an overwhelming traumatic experience.

Anxiety is viewed as a phase of panic-stricken reaction upon initial recognition of the magnitude of the traumatic event. This reaction should not be confused with anxiety as a trait-like character concept.

Denial, considered a more problematic reaction to verify due to its subtle and often conflicting aspects,

is seen as a defense mobilization against painful realization of the implication of one's condition, including the expectancy of recovery from the impairment.

Depression, a reaction often observed among adventitiously-impaired persons, is typically conceived to reflect the initial realization of the loss of one's prior physical prowess stemming from the sustained bodily insult. It is generally equated with a reactive response of bereavement for the lost body part or function.

Internalized anger is viewed as the exhibition of self-directed bitterness and resentment often associated with feelings of guilt and self-blame. This reaction should be most evident in persons who realize their impairment is a chronic condition [21].

Externalized hostility toward people, objects or other aspects of the environment occurs when the person with an impairment appears to be retaliating against his or her imposed functional limitations. Externalized hostility should be particularly evident with increasing chronicity (i.e. passage of time from the onset of the impairment) [22].

Acknowledgment is made up of the cognitive recognition (i.e. intellectual acceptance) of the future implications stemming from the impairment and the gradual integration of the functional limitations associated with one's condition into one's self-concept.

Adjustment reflects an affective internalization (i.e. emotional acceptance) of the functional implications of an impairment into one's self-concept coupled with behavioral adaptation and social reintegration into the newly perceived life situation.

Although most investigators have studied just one of these reactions, a few have undertaken to show empirically the existence of a set of phases of psychosocial adaptation to disability. For example, Westbrook and Viney [11] investigated reactions (i.e. anxiety, directly and indirectly expressed anger, depression, helplessness, uncertainty, positive feelings) to various chronic illnesses using content analysis of their subjects' verbal responses to structured interview questions. The pattern of reactions of the persons with chronic illnesses inferred from their responses was shown to be different from the pattern of reactions of persons without chronic illnesses, attesting to the psychological distress of the former group. Bracken *et al.* [23] examined several reactions to spinal cord injury (i.e. denial, anger, anxiety, depression), but did not investigate temporal changes in these reactions nor the prediction of their salience from other variables. Other attempts to uncover sets of reactions include the clinical studies of Shontz [24], who examined the phases of shock, realization, defensive retreat, acknowledgment and adaptation, and of Drotar *et al.* [25] who observed shock, denial, depression, anger, adaptation and reorganization.

Adaptation to traumatic disability and to chronic illness

It is useful to make a distinction between adaptation to disability associated with a traumatic event, such as a spinal cord injury, and adaptation to disability associated with a chronic illness, such as multiple sclerosis (MS). With a traumatic event, the onset of disability is sudden with physical stability achieved more or less soon afterward. The onset of a chronic illness is typically gradual and insidious. The course of the illness is often uncertain and marred by periods of deterioration and remission. The distinction between these two conditions, although only occasionally intimated in the literature [26–28], is of theoretical importance when conceptualizing the unfolding manner of adaptation to life crises generally and to medical conditions specifically.

The reaction of shock, for example, will generally be experienced following the onset of a traumatic condition (e.g. amputation, spinal cord injury, head injury, myocardial infarction), but it may have a more narrow psychic focus when the person is confronted with the diagnosis of a life-threatening or end-stage disease (e.g. cancer, AIDS). Shock may not be experienced at all, however, by persons with a gradually deteriorating and uncertain medical condition (e.g. arthritis, Parkinson's disease, diabetes, MS). Similarly, the reactions of anxiety and depression may be manifest in a variety of clinical forms depending upon the disabling condition. When a chronic illness is involved, anxiety and depression, which often share common ingredients, are manifest as fear of body damage, fear of an uncertain future and even fear of death [29, 30]. Following a sudden, traumatic physical disability, however, anxiety and depression typically include grieving for a lost body part or function and psychomotor retardation [31]. In other words, whereas chronic illness-related anxiety and depression appear to be future-oriented (fear of the unknown, feelings of hopelessness), traumatic event-related anxiety and depression appear to be more past-oriented (grieving for the loss of an intact physical or cognitive ability).

As a final example, the reactions of acknowledgment and adjustment are likely to take different forms depending on whether the disability is related to a chronic illness or a traumatic event. When a chronic, especially a life-threatening, illness is the condition, acknowledgment and acceptance would constitute some form of recognition or internalization that the condition is likely to worsen or that death is imminent. Psychosocial adaptation under such conditions is almost inconceivable. Following a traumatic event, however, adaptation to a permanent and relatively stable loss or alteration of function implies healthy reconstruction of one's life followed by efforts to successfully reintegrate oneself into society.

It is noted, however, that the study of adaptation to either a traumatic disability or to a chronic illness is complicated by many intervening factors. These include cognitive impairments associated with the impairment (e.g. brain vs physical-only involvement), timing of the impairment, premorbid coping mechanisms and skills (e.g. level of successful coping with previous life crises), severity of the resultant functional limitations, and the availability of a supportive family network and social resources [26, 28, 30, 32].

Psychological and social dimensions of adaptation to disability

It is customary for theoreticians and researchers concerned with the process of psychosocial adaptation to disability to view it as a unitary concept with psychological and social dimensions that are considered to be theoretically unique yet share common clinical variance. The psychological reactions to a disability are internally-oriented—they revolve around personal experiences and intense emotions such as anxiety, depression and anger. The social adaptation to a physical disability, however, is externally-oriented—it relates to interpersonal experiences and actions at home, work and in the community at-large.

Put differently, the psychological phases of adaptation to disability typically constitute a process that culminates in greater personal openness to experiences, improved self-esteem, heightened self-awareness, and, in general, acceptance of and successful coping with the aftermath of a personal loss. The social phases of adaptation to disability, on the other hand, are components of a process whose unfolding reflects a movement from social withdrawal and interpersonal distancing (i.e. behaviors manifested during anxiety and depression), to actions against others (i.e. oppositional tendencies, observed during internalized anger and externalized hostility), and finally to collaboration with others (i.e. acquisition of social skills, social interaction, and participation in familial, social, vocational, and avocational activities). A social adaptation process has been posited that unfolds parallel to the psychological adaptation process as the person with a disability moves from a state of dependency upon others to a state of independence and inter-dependence with others [17, 33].

Instruments to measure psychosocial adaptation to disability

Data concerning a process of psychosocial adaptation to disability originate from studies adopting a limited number of measuring instruments of widely varying psychometric adequacy [34, 35]. The Arthritis Impact Measurement Scales [36] is an example of a carefully developed, reliable, practical and comprehensive multidimensional instrument that is valid for studying psychosocial adaptation in persons with arthritis. Other instruments, including the Mental Adjustment to Cancer scale [37], the Portland Adaptability Inventory [38] (for persons with traumatic brain injury), the Psychosocial Questionnaire for Spinal Cord Injured Persons [39], the Glasgow Assessment Schedule [40] (for persons with traumatic brain injury), the Nottingham Adjustment Scale [41] (for persons with an acquired visual impairment), and the Washington Psychosocial Seizure Inventory [42] (for persons with convulsive disorders), lack sufficient data as yet on crucial psychometric characteristics to recommend them as measures of psychosocial adaptation in persons with these specific disabilities.

Several general measures have been developed that operationalize adaptation to chronic illness and disability with unidimensional scales, making them less than ideal for investigating adaptation as a set of distinct phases. For example, responses to individual items on the Acceptance of Disability scale [43] are summed to yield a single score representing the degree of acceptance of one's physical disability. Similarly, Osuji's Acceptance of Loss scale [44] is scored by totalling a subject's responses resulting in a single score ostensibly measuring one's level of adjustment to a physical disability. Bell's Disability Scale of Adjustment [45] is another univariate scale developed to measure a person's degree of acceptance of an orthopedic disability (i.e. spinal cord injury), perceived to range from passive rejection, through active rejection and passive acceptance, to active acceptance. No data are provided, however, on how to convert derived scores to measure phases of adjustment (e.g. passive rejection, active acceptance).

The unidimensional conception of adaptation evident in these instruments ignores the fact that reactions to disability have multiple antecedents and that the behaviors they predispose the person to manifest have multiple facets. The Reactions to Impairment and Disability Inventory (RIDI) [14] may furnish researchers with a more useful multidimensional measure. The RIDI provides information on eight reactions to the onset of disability, namely: shock; anxiety; denial; depression; internalized anger; externalized hostility; acknowledgment; and adjustment. The results of detailed psychometric analyses of initial data suggest that the scales have good item properties, are easy to administer and score, are reliable, and have adequate construct validity. Two subsequent investigations [46, 47] demonstrated the utility of the RIDI for investigating the process of psychosocial adaptation to disability.

Ordered phases of psychosocial adaptation

To show that adaptation is a temporally ordered, hierarchical process, it is necessary to identify a sequence of reaction phases for a population under study [48, 49]. While overlap may exist among the intervals associated with temporally juxtaposed phases, the order of emergence of the phases should remain invariant. The researcher may observe the behavior of a small sample of persons (the cohort)

at different times to study time-ordered associations. An illustration of this longitudinal research design is the work of Lezak and colleagues [38, 50] who collected data at 1-year intervals up to 5 years post-trauma from persons with traumatic brain injuries. Three patterns of change were observed: continuing psychosocial dysfunction over time, gradual and variable improvement over time, and a curvilinear pattern in which gains were observed within the second half of the first year after injury (i.e. anxiety and depression decreased) but then were lost in subsequent years.

Longitudinal investigations may yield rich data, but they are generally time-consuming and expensive endeavors. An alternative is to obtain data from a cross section of the population at one time, with the hope that the characteristics of the persons sampled will represent each of the phases of the process being investigated. Data-analytic procedures, such as scalogram analysis [51], unfolding theory [52], and ordering theory [53], are then used to test the hypothesized phase sequence. This design, although unable to delineate the exact timing of acquired and deleted phases, may reveal a time-ordered sequence of the process studied. Cross-sectional studies are useful for the identification and isolation of salient variables and relationships that can be studied in detail with longitudinal designs.

Livneh and Antonak [46] recently investigated a hypothesized temporal order of phases of psychosocial adaptation to disability in a cross-sectional sample of persons with various physical disabilities using unfolding-theoretic analysis [54]. The results obtained revealed a phase ordering that did not coincide with the hypothesized ordering (i.e. shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgment and adjustment). A set of five non-adaptive reactions (depression, internalized anger, shock, anxiety and externalized hostility) preceded and was distinguishable from a set of two adaptive reactions (acknowledgment and adjustment), with the reaction of denial intermediate to these two polar sets.

Suspecting that the failure to recover the hypothesized order was an artifact of examining the process with a linear analytic technique, these researchers subsequently investigated the relationships among the eight reaction phases using ordering theory, a nonlinear analytic technique, with data from a sample of persons with non-congenital physical impairments [47]. Acknowledgment and adjustment were seen as distinct final phases, suggesting that the individual may acknowledge his or her disability but fail to achieve full adjustment to it. Reaching one of these adaptive phases was dependent upon passing through prerequisite phases of anxiety, depression, internalized anger and externalized hostility. Experiencing shock was apparently prerequisite to experiencing depression and internalized anger, whereas denial was independent of the other reactions. While the authors cautioned that the obtained reaction phase hierarchy was not universal and needed to be cross-validated with other samples, their results demonstrated the fruitfulness of conceptualizing psychosocial adaptation to disability as a nonlinear, multidimensional, hierarchical process.

Impairment-specific adaptation

There has been an increase in the past two decades in research concerning psychosocial adaptation to disability among samples of persons with specific illnesses and physical impairments (e.g. spinal cord injury, epilepsy, myocardial infarction, traumatic brain injury, diabetes, cancer, MS). Few studies, however, have attempted to discover empirically whether variability in the process of adaptation is impairment-specific and, if so, what characteristics (e.g. impairment-related, situational, demographic) are predictive of this variability [18].

The remainder of this article will concern the research literature on psychosocial adaptation among persons with multiple sclerosis because this literature is rich in illustrations of the issues raised in preceding sections of this article. In the next section we provide a brief introduction to MS and then review the research on psychosocial reactions to this chronic disease, an enterprise that has concerned researchers for more than 100 years. Based upon this review, we will elucidate in the final section of this article the significant research problems concerning the study of psychosocial adaptation to disability that have limited the usefulness of the information collected. We conclude by offering modest suggestions for future research investigations in this domain of psychological inquiry.

PSYCHOSOCIAL ADAPTATION TO MULTIPLE SCLEROSIS

Multiple sclerosis

Multiple sclerosis is a chronic, progressive, demyelinating disease with onset commonly between ages 20 and 40 years. MS is the most common acquired neurological disease in young adults in North America and Europe with a reported incidence in the United States varying from 30 to 100 per 100,000 persons [55–58]. Two to three females are afflicted for every male. The disease is five times more common in temperate latitudes than in the tropics.

While the cause remains unknown, it is thought to be an autoimmune disease in which the myelin (the covering of the nerve fibers) is treated as foreign by the body's defenses and attacked, resulting in lesions (scar tissue or plaques) that delay or block the passage of nerve impulses. This leads to an array of symptoms varying from person-to-person, depending upon which parts of the brain and spinal cord are affected, and within a person from time-to-time, including: numbness; impaired mobility; paralysis;

spasticity; fatigue; vertigo; problems in bladder control; sexual dysfunction; difficulty in communication; cognitive deterioration; and visual impairments. The rate of progression of the disease is unpredictable. The person typically experiences cyclical periods of new or worsening symptoms (exacerbations) lasting 2 to 3 weeks alternating with periods of symptom stability or decrement (remissions). While in most individuals the period between exacerbations may extend to 5 years, as many as 10% of the population exhibit continuous progression of the disease without remission.

There is no cure for MS, nor are there preventive measures. Treatments can offer symptomatic relief. Drugs can be used to alleviate inflammation, to suppress the immune system, and to treat pain, depression, incontinence and spasticity. Physical therapy can increase mobility and prevent disuse atrophy of the muscles. The neurologist confirms the diagnosis of MS by the gradual elimination of other possible neurological diseases, a process that may take from several months to several years in extreme cases. Tests that may be performed to provide confirmatory data include: analysis of cerebrospinal fluid obtained from lumbar puncture, tracing patterns of evoked electrical activity of the brain, computerized tomographic scanning and magnetic resonance imaging. MS itself is not fatal, but the individual may die from the general hazards associated with advanced chronic diseases such as infections, pulmonary embolism, complications of pathologic fractures, or pneumonia.

Reactions to multiple sclerosis

Experts agree that a determination of the emotional and psychosocial reactions of persons with MS may lead to more effective clinical management and improved long-term rehabilitation planning [16, 59–63]. Although the major difficulties in rehabilitation of persons with MS are variability of symptoms and the uncertain prognosis for the course of the disease, the person's response to rehabilitation opportunities will be limited if he or she has not made a successful adaptation to the disease and its subsequent disabilities. Problems of affect of a person with MS may be amenable to change if the clinician can determine the person's reaction phase and select an appropriate intervention strategy designed to teach efficient coping skills.

The psychosocial reactions of persons with MS have been a concern of researchers since the 1870s [64]. In the middle decades of this century frequent unsuccessful attempts were made to discover a universal personality among persons with MS [65–68]. Most studies of reactions of persons with MS have relied on clinical case reports, anecdotal records, retrospective self-report data obtained from mail surveys of dubious psychometric adequacy, or from client and family interviews [62, 67, 69–80]. Other investigators have attempted to construct personality profiles using data from instruments such as the MMPI [81–89], but no clear and consistent profile has yet emerged [16, 90]. The results of more than 40 years of research do confirm, however, that the person must confront and attempt to cope with profound stresses associated with MS, including the unknown cause, variability of symptoms, ambiguity of diagnosis, unpredictability of exacerbations and remissions, lack of a cure and the reactions of other persons to visible symptoms such as spasticity or ataxia.

Among the many reactions to MS that have been reported (e.g. aggressiveness, anger, apprehension, anxiety, denial, emotional liability, dependency, euphoria, helplessness, hopelessness, hostility, invalidism, irritability, low drive, resignation, shock), the most commonly studied reaction has been depression [69, 70, 75, 79, 91–97]. The diagnosis of depressive disorder based on behavioral indices in persons with MS has been a consistent finding but the contribution of depression to the onset and progress of the disease is unproven. Moreover, the available data are not sufficient to validate the contention that emotional and intellectual impairments in persons with MS are clinical manifestations of the neurobiological impairment and not reactions to the neurological disease [16, 98].

The psychosocial functioning of persons with MS has occasionally been related to that of persons diagnosed with other neurological disorders and chronic diseases to identify similarities and differences. The assumption is if it can be shown that persons with MS evince reactions similar to those of persons with other impairments, then clinicians may increase rehabilitation success by selecting from intervention strategies validated for other populations. Comparison groups have included: muscular dystrophy [79], traumatic brain injury [84], Parkinson's disease [66, 68], poliomyelitis [66], epilepsy [94, 99], amyotropic lateral sclerosis [94], spinal cord injury [81, 91], arthritis [81, 100–102], hypertension [100], cardiac disease [101, 102], and diabetes [101].

For example, Tan [99] compared psychosocial adjustment of three groups: adults with epilepsy, adults with MS, and adult volunteers from a church organization. Individuals in both of the chronic illness groups scored low on a scale of emotional adjustment in comparison with non-impaired individuals with the items most frequently checked relating to anxiety, anger, denial and depression.

Other findings of this line of research suggest that persons with MS:

(a) express more variability in their reactions to the disease [91]; and
(b) express more intense depressive reactions than do persons with other diseases and physical impairments [79, 84, 94, 98].

A recent study by Pollock *et al.* [100], however, raised the issue that comparative investigations may be flawed by sampling bias, confounding of

sample characteristics and measures of reactions, and instrumentation weaknesses. In a well-designed study, they found no differences in their measures of psychological adaptation among groups of persons with MS, hypertension and rheumatoid arthritis, suggesting to them that the process of adaptation was similar for the three groups.

Characteristics associated with reactions to multiple sclerosis

A number of investigators have analyzed data on demographic, personality, and illness-related variables and reactions to MS [62, 90, 94, 95, 97, 103–106]. McIvor *et al.* [90] related depression to a set of variables (e.g. age, chronicity and severity of disability, family and peer support, remission status) and found that persons who were older and more disabled were more depressed, and those in remission were least depressed. Their finding that loss of social support was a factor in depression was confirmed by the results of a study by Wineman [106] who discovered that adaptation to MS was directly related to the person's perceptions of support and inversely related to functional disability and perceptions of nonsupport. Pavlou and Counte's [105] analyses of data on attitudes, stereotypic beliefs and knowledge about MS showed that the best predictor of all three dependent measures was the person's educational level, with age the next most important for predicting knowledge and beliefs, and the number of hospitalizations for exacerbations the next most important predictor for attitude. Related studies [63, 107] confirmed that degree of physical disability and psychosocial adjustment were inversely related.

Another variable thought to influence the person's adaptation and rehabilitation potential is self-appraisal of the disabilities associated with the disease. Differences between a person's perception and the perceptions of others (i.e. spouses, family members, clinicians) are hypothesized to lead to marital stress, family conflict, low level of participation in rehabilitation programs and poor vocational adjustment. This suggests that rehabilitation goals and intervention strategies should vary with the person's appraisal of disability, and that counselling goals for the family should include an assessment of the spouse's and children's perceptions of the disease and associated disabilities [108, 109]. Power's [62] in-depth interviews of persons with multiple sclerosis and their families revealed that fewer than half the family units were making a successful adaptive response to the diagnosis of MS (i.e. reporting acceptance of the diagnosis and demonstrating adjustment to symptoms and functional limitations of the disease). Among the reactions expressed by the family units considered to be maladjusted were: shock and confusion over the initial diagnosis, denial of the diagnosis, anger over the presence of the disease, anxiety and insecurity over the future course of the disease, and hopelessness. When the family's and person's perceptions and expectations did not coincide, family stress and tension resulted. Spouses felt trapped, overwhelmed, and resentful and frequently displayed disruptive behavior (e.g. excessive drinking and fighting). These findings were confirmed in a study of families of persons with MS [101].

Models of adaptation to multiple sclerosis

Few researchers have conceptualized the reactions of persons with MS as phases of an overall process of adaptation to MS and the disabilities associated with it. Stewart and Sullivan [110] argued that reactions during the pre-diagnosis period should be distinguished from reactions during the post-diagnosis period, but provided no empirical data. Wassem [102] proposed a model to predict adaptation to disease (including MS) based on Bandura's social learning theory, but operationalized adaptation with a unidimensional measure. Noting that the consequences of MS included changes in economic (e.g. loss of employment, cost of care), social (e.g. changes in family integration, reduction in social contacts and recreational activities), and psychological circumstances (e.g. loss of sexual potency, changes in body image, loss of self-esteem), Marks [60] proposed a model in which adaptation to MS was thought to be related to seven variables classified in one of three dimensions (illness-related, environmental and personality characteristics). The analyses of data obtained, however, did not constitute a reasonable test of this model because all the variables were conceptualized as unidimensional and their interrelationships were investigated using simple linear bivariate correlation analyses.

Only one investigation was located that conceptualized reactions to MS as a hierarchical adaptation process. Starting with Kübler-Ross's [111] model of reactions to death and dying, and using data from mail surveys and follow-up interviews of persons with MS, Matson and Brooks [112] proposed an adaptation model consisting of four temporally ordered phases: denial, resistance, affirmation and integration. The authors acknowledged that progress toward integration may be slow and a person with MS may move back and forth on the adaptation continuum because of transient circumstances, such as exacerbation of the symptoms and stressful life events. Brooks and Matson [1] obtained additional mail survey and interview data 7 years later from individuals of the original sample. Unfortunately, they operationalized adaptation as a unidimensional variable and did not provide any empirical data to test their model.

RESEARCH PROBLEMS AND RECOMMENDATIONS

Previous reviews of the research concerning the emotional and psychological impact of multiple sclerosis [16, 84, 86, 103, 113] have isolated significant research problems that have limited the

usefulness of the information collected. These concerns included:

(a) small sample sizes;
(b) sample selection bias (e.g. the use of hospitalized patients, consecutive self-selected persons or nonrepresentative volunteer samples of convenience);
(c) failure to test research hypotheses with appropriate statistical techniques;
(d) use of retrospective self-report data obtained from mail surveys or from client and family interviews;
(e) use of nonobjective and obtrusive direct measures of reactions;
(f) the absence of adequate comparison groups;
(g) failure to control for or partial out the influence of client response style variables (e.g. acquiescence, social-desirability responding);
(h) reliance on cross-sectional as opposed to longitudinal research designs;
(i) observer bias inherent in subjective measurements of reactions; and
(j) the confounding of demographic, illness-related, and situational variables with measures of reactions to disability.

Our review confirms these observations and points to two additional problems:

(k) the failure to conceptualize psychosocial adaptation to disability as a multidimensional process; and
(l) the lack of psychometrically sound instruments to operationalize the concept of adaptation.

The study of the relationship between chronicity and adaptation to MS provides an example to illustrate the difficulties encountered by researchers and the basis for these recommendations. Results of research using samples of persons with impairments other than MS have indicated that adaptation increases with increasing chronicity [4, 14, 46, 114, 115]. Yet, studies have consistently reported the lack of a linear relationship between chronicity and adaptation to MS in a variety of samples using a variety of measures [63, 90, 92, 100, 105, 116, 117]. A plausible explanation for this unexpected finding may be found by examining the results of the investigations by Matson and Brooks [112] and by Brooks and Matson [1]. Namely, these two variables are more correctly viewed as curvilinearly related.

As predicted in the model of Stewart and Sullivan [110], non-adaptive reactions of anxiety, irritability and depression are common during the period when symptoms are first apparent. Upon diagnosis of MS, a brief period of acceptance occurs because of reduction of uncertainty and associated stress, the increased support from the person's family, the person's realization that death is not imminent, and the initiation of therapeutic symptom treatment. This is followed, however, by a period of pronounced and prolonged disintegration, with the reappearance of the reactions of depression, irritability, anger and hostility. Regressions to earlier phases of the hypothesized adaptation process are predictable from the renewed life crises associated with unexpected exacerbations of physical symptoms and the resultant imposition of disability.

Depending on the course of the disease and a variety of situational variables, some persons with MS may gradually evince acceptance of and successful adjustment to the disease. Other persons with MS may continually cycle through a sequence of non-adaptive and quasi-adaptive reactions consequent to repeated cycles of exacerbations and remissions. The failure of research investigating the relationship between chronicity and psychosocial adaptation to disability to demonstrate the predicted linear relationship is understandable under these circumstances. A hypothesized complex curvilinear relationship between chronicity and adaptation cannot be tested with univariate statistical analyses of data obtained using unidimensional instruments with small and nonrepresentative samples in cross-sectional research.

It is recommended that researchers investigating psychosocial adaptation to MS should use:

(a) representative sampling;
(b) a longitudinal design;
(c) an instrument that operationalizes adaptation as a hierarchical process composed of more than a single dimension; and
(d) statistical tools that remove the independent effects of confounding variables.

The results obtained should lead to a better understanding of the individual's emotional and psychological reactions and the characteristics associated with them, and consequently, to the selection of appropriate intervention strategies designed to teach persons with MS efficient coping skills.

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