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The NLN Mission Statement

The mission of the NLN is to create awareness of lymphedema through education and to promote and support the availability of quality medical treatment for all individuals at risk for or affected by lymphedema.

The NLN is dedicated to:

- promoting research into the causes, prevention and treatment of lymphedema;
- securing adequate insurance coverage for medically necessary, safe and effective treatment;
- expanding the number and geographical distribution of lymphedema treatment facilities and certified therapists.

To achieve these goals, the NLN disseminates information about lymphedema to health care professionals so they can appropriately counsel their patients on its avoidance, and prescribe safe, effective treatment for those affected by this condition. The NLN also provides this information to the general public.

Barriers And Facilitators To Successful Lymphedema Therapy: The Role Of Adherence

By Steven C. Palmer, PhD

Although much progress has been made in the treatment of lymphedema, little is known about the determinants of longer-term outcomes. This is particularly troublesome as initially positive results can be difficult to maintain and treatment failures require a great deal of remedial therapy. Maintenance regimens are complex, and although some of the current recommendations are based as much on clinical lore as clinical trials, they are the current standard of care.

Complex decongestive physiotherapy (CDP) or variants, such as complex physical therapy (CPT), require patients to undertake some combination of skin care, manual lymph drainage, physical exercise, and the use of compression bandages and garments to maintain pressure gradients. Completing this complex set of tasks is further complicated as patients need to perform these in the context of recovery from a life threatening illness and all need to integrate them into their on-going life roles and demands. Further, once patients are in a maintenance phase of treatment, there may be few obvious results of their efforts; although success may be maintained, no obvious additional benefits are seen.

Adherence

We use the term "adherence" to describe the process by which patients' behaviors match the recommendations they have agreed upon with their healthcare professionals. This differs from the traditional notion of "compliance" in that patients are active participants in the process, negotiating behavioral goals in partnership with professionals, rather than receiving treatment demands and needing only to be obedient to succeed. This places an emphasis on communication between provider and patient, a process that likely plays a substantial role in the success achieved by patients. Although it is widely agreed that adherence plays a major role in

successful lymphedema management, the determinants of adherence and what can be done to enhance patient adherence are underspecified.

Adherence is best thought of as a process rather than a static event, and adherence across time and tasks requires a number of conditions to be met. Adherence presumes that individuals have adequate skills to perform the agreed upon tasks, as well as more general skills at recognizing and overcoming barriers to performance. Thus, assessing the skill with which individuals can perform exercises, manual drainage, and wrapping, and then providing remediation are necessary prerequisites to adherence, but may be inadequate to ensure that individuals will be successful over the long term.

Long-term success likely depends on a number of factors that will be discussed below, although more general problem-solving skills are also important, and examining both patients' and providers' abilities to recognize and overcome barriers to adherence may provide an opportunity to improve the chance of success.

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Adherence is also based on the understanding that individuals have regarding the tasks they are agreeing to perform. Without an understanding of the reasons for a given task and the consequences of non-adherence, individuals are less likely to be adherent. Knowledge and understanding may play a particularly important role when the best outcome one can anticipate is maintenance of a positive result rather than amelioration of a problem, as patients may see no added "benefit" to reinforce their adherence. Motivation underlies adherence, and individuals who have made a commitment to performing behaviors are more likely to persist when difficulties arise. Motivation also helps individuals habitualize their behaviors and integrate them into their daily lives, increasing the chance that behaviors will persist. Finally, adherence is predicated on having the resources necessary to perform the agreed upon behaviors. If an individual cannot obtain the necessary resources to complete their tasks, they cannot fully adhere; adherence to the wearing of an ill-fitting compression garment can at best be described as partial adherence.

Generalization From Other Populations

Although there are very few data examining adherence in lymphedema, there is a large body of literature concerning adherence in other chronic conditions, such as asthma, hypertension, diabetes, and transplantation (e.g., Bender, 2003; Bender, Milgrom, & Apter, 2003; De Geest, Doobels, Fluri, Paris, & Trooster, 2005; Koenisberg, Bartlett, & Cramer, 2004; Waeber, Burneir, & Burneir, 2000; Walker & Usher, 2003). Studies such as these have provided a number of insights into the general adherence process, as well as a means of organizing the individual, social and systemic factors that are likely to influence adherence to lymphedema management.

Adherence is a substantial problem in the management of other chronic conditions, and relates to outcomes. In a 3-month study of children with asthma, adherence to inhaler use was 68% among those with good disease control, but only 14% among those who experi-

enced an exacerbation during the study (Milgrom et al., 1996). Similarly, non-adherence has been found to be a factor in 90% of rejection cases after the first year following cardiac transplant (De Geest, Moons, Dobbels, Martin, & Vanhaecke, 2001); and non-adherence is a primary factor in the control of diabetes and hypertension.

Rates of adherence vary across tasks and diseases, but are generally less than optimal. In the U.S., less than 2% of individuals with diabetes fully adhere to the recommendations of the American Diabetes Association (Beckles et al., 1998). Among asthma patients, rates of non-adherence to the primary task of filling a prescription vary from 6% to 44% (Beardon, McGilchrist, McKendrick, McDevitt, & MacDonald, 1993; Cerveri et al., 1999; Krogh & Wallner, 1987; Rashid, 1982; Saunders, 1987; Waters, Gould, & Lunn, 1976); and even when prescriptions are filled, adherence to recommended dosage can be as low as 37% over a 4-week period (Mawhinney et al., 1993). Only 20% to 80% of individuals with hypertension have been shown to adhere to regimens (Costa, 1996). Even among immediately life-threatening conditions such as cardiac transplantation, non-adherence rates range as high as 54% (see De Geest et al., 2005).

Assessing Adherence

Assessment of adherence is a difficult task, and there is little consensus about how best to assess precisely how adherent a patient has been. Monitoring outcomes is an important step (that is, monitoring the degree of success in managing lymphedema), but factors other than adherence often influence less than optimal outcomes. Providers are notoriously poor at estimating how adherent their patients are, tending to over-estimate adherence. When asked subjective questions about their own adherence, patients tend to over-estimate when reporting adherent behaviors, but are more accurate when reporting problems in adherence. In addition, adherence tends to be independent across behaviors, and adherence to one set of behaviors (such as skin care) may have little relationship to the degree to which an individual is adherent to other behaviors (such as exercise or manual

lymphatic drainage). Thus, classifying an individual as "adherent" or "non-adherent" is not a particularly useful exercise.

The form that assessment of adherence takes may play an important role in understanding how adherent an individual is to a set of behaviors, and may allow for examination of barriers to adherence that differ across behaviors. Individuals tend to be more accurate in reporting their adherence when provided with specific questions about specific behaviors. For example, patients are more accurate when responding to the question, "How many times in the past week were you able to wear your compression garment? For how long each time?" than they are when responding to global questions such as, "How have you been doing with the compression garment?" Such specific questions lead directly to examination of barriers to adherence. When combined with monitoring of outcomes, this strategy may provide better insight into an individual's adherence behaviors.

Modeling Adherence

A number of models have been proposed to understand the factors that influence adherence, but none has proven superior to all others. What they provide is a way to organize the various factors that are likely to influence adherence in discrete categories and make predictions about how these factors interact to assist or hamper adherence. Perhaps the dominant model in healthcare delivery remains the *biomedical model*, which views adherence as a patient-centered phenomenon. Patients are viewed as recipients of treatment recommendations, and non-adherence (often termed non-compliance) is seen as a reflection of patient and, perhaps, disease characteristics. Thus, interventions to improve adherence are targeted at the patients who control the adherence tasks.

The *behavioral model* suggests that adherence results from exposure to the reinforcement and punishment that allow learning to take place, and that adherence is a learned behavior similar to all others. Individuals are exposed to cues in the environment (e.g., the beginning of swelling in the hand) that prompt a behavioral response (e.g., manual



lymphatic drainage), and the consequences of this response (e.g., reduction in edema) either increase or decrease the likelihood that the behavior will occur in the future. Thus, interventions require that the environment be controlled and manipulated to provide adequate cues and appropriate consequences for behavior – a difficult task for other than very circumscribed behaviors with immediate results.

The *cognitive or cognitive-behavioral model* stresses the role that expectations, attitudes and beliefs play in determining adherence. A number of specific models fall under this rubric, such as the health-belief model and the theory of reasoned action, but all these emphasize that individuals develop beliefs and expectations about themselves, their environment, and the likely outcome of their behaviors, and these expectations interact to determine how individuals behave. Thus, interventions focus on changing the way that patients view their ability to carry out actions, the value of the action itself, and/or the likely outcome of carrying out the action. An

important concept to come from cognitive models is *self-efficacy*, the confidence that an individual has that she will be successful in carrying out a given behavior. Self-efficacy has repeatedly been shown to relate to the likelihood success in adhering to new behaviors.

In *self-regulation models* individuals are seen as active problem solvers who are attempting to reach some given goal regarding their health. Individuals form a "common sense model" of their illness that takes into account perceived causes, time-line, the likelihood of a cure, seriousness, and likely outcome. This common sense model continually interacts with an individual's emotional reaction to the illness to prompt coping. Adherence behaviors are the result of the individual attempts to reduce the difference between their desired health state and their current health state in the context of their beliefs about the illness and their emotional reactions. Feedback from the environment helps determine whether or not one is approaching their goal, and whether or not one should maintain their adherence behaviors.

What Factors Contribute To Adherence

Perhaps the most straightforward way of addressing factors that influence adherence is the multidimensional approach adopted by the World Health Organization (2003). This approach posits that adherence is determined by the interaction of five dimensions: Healthcare team and system factors, Socio-economic factors, Therapy-related factors, Condition-related factors, and Patient-related factors. Of note here is the idea that the patient plays a role in adherence, but is not the sole determining factor. Thus, non-adherence is not a 'patient driven' problem, but a problem that arises from the interplay of a number of complex relationships, any of which may be seen as a potential area for intervention to improve adherence. Though more complex than a traditional, patient-centered approach to adherence, this multidimensional approach has the benefit of providing patients and treatment staff with a structure by which to organize the various influences on adherence so that

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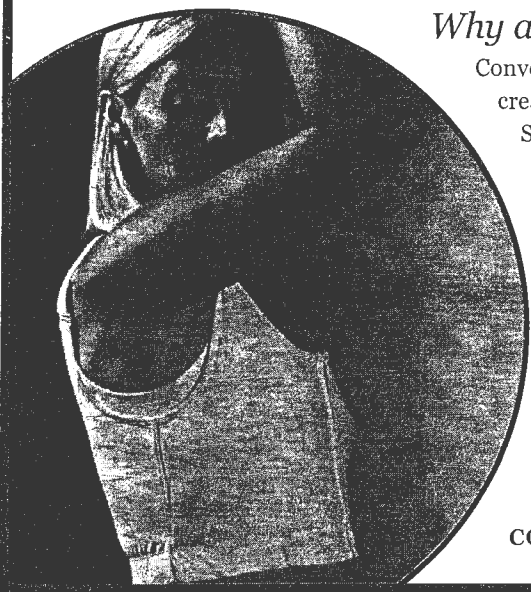
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Barriers...

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appropriate problem solving can take place. As there are few data on predictors of adherence in the lymphedema patient population, discussion of these factors must rely on applying what is known about adherence in other groups to the specifics of the lymphedema population.

Healthcare Team And System Factors

Healthcare team and system factors describe the interaction between the patient and the care delivery team. These factors include not only the interpersonal relationship between individuals, but the ability of the healthcare team to impart knowledge, assess skills, provide adequate feedback on performance, and establish follow-up contact. There is evidence that good interpersonal relationships between patients and providers can improve adherence in hypertension and diabetes, and that poor relationships decrease the likelihood of adherence. Another factor centers on the provider, and includes the knowledge and training that providers bring to the interaction, and the incentives that the provider receives for providing adequate care. Although inadequately studied, healthcare systems in which providers are well trained, have adequate time for consultations and follow-up, are provided with feedback, and are reimbursed for their performance are likely to enhance adherence. Additionally, providers who are knowledgeable and well trained need to have the skills to impart this knowledge to their patients in a way that allows them to master the skills required to perform the task.

Socio-Economic Factors

Adherence presumes adequate resources, including both money and time. If patient supplies are non-reimbursable by third-party payers, adherence is likely to decrease. Poverty, illiteracy, unemployment, and the cost of care have been shown to decrease adherence in asthma and hypertension patients. Similarly, patients are more likely to adhere when they have

adequate time and competing demands are decreased. This may be particularly true for women who have numerous role responsibilities; female gender has been associated with decreased adherence to exercise among individuals with diabetes. Older individuals, particularly those with additional co-morbidities that require care, may be at increased risk of non-adherence. An often-overlooked influence on adherence involves family relationships. For a number of conditions, poor support from family members surrounding the adherence task specifically, or dysfunctional family relations more generally have been related to poorer adherence.

Condition-Related Factors

Not surprisingly, the demands placed on an individual by a disease state or condition influences adherence. As mentioned previously, the presence of additional co-morbid illnesses, such as depression, drug or alcohol abuse, or physical co-morbidities are likely to have a negative effect on adherence. This may be a particular problem for conditions such as breast cancer in which age increases risk for the illness and co-morbid conditions. Lymphedema itself may also influence adherence to maintenance treatment; more severe disease or more severe symptoms not only require more intensive treatment, but also make adherence a more difficult task. Similarly, severity of disease may affect the level of disability that individuals experience, and there is strong evidence that the level of disability negatively influences adherence.

Therapy-Related Factors

One of the most robust findings in the adherence literature concerns aspects of the therapy itself: The more complex and complicated a therapeutic regimen is, the less likely patients are to be able to adhere to all aspects of it. Duration of treatment also plays a role; treatments that extend farther in time are less likely to foster adherence. This is a particular difficulty in the management of lymphedema, as treatments are highly complex, require a great deal of skill to perform and extend far into the future. Moreover, dismantling studies, which

isolate active components of therapy and might allow for either tailoring of intervention or scaled down interventions, have yet to be performed in lymphedema treatment. Thus, there is no empirical basis for modifying the standard of care to make adherence an easier task. In the literature concerning other chronic conditions, condition-related factors that decrease adherence include previous treatment failures, tolerability of side effects and delay of beneficial effects. Again, these may make the task of adherence to lymphedema management even more difficult, as many individuals will experience at least some discomfort from the procedures and/or some degree of relapse, and the goal is often not an immediately recognizable decrease in edema so much as to prevent new difficulties from arising.

Patient-Related Factors

From the biomedical perspective, patient-related factors are the traditional focal point for understanding and intervention to improve adherence. These factors include but are not limited to an individual's knowledge about their condition, skill level and comfort with technical procedures, motivation to manage their condition, confidence in their ability to perform the adherence task, and expectations for success. The literature consistently demonstrates that these factors influence adherence to difficult health behaviors. Individuals can and should be supported in their beliefs about the likelihood of their own success in managing lymphedema, but it may be equally important that their skill level be assessed for each of the tasks they are to perform and remedial training be provided as necessary. Other patient-related factors that need to be considered include stress and forgetfulness, perceptions of need for continued treatment or faulty risk perceptions, and the degree to which individuals are involved actively in the monitoring of their disease management.

Motivation and confidence are pivotal constructs for understanding and enhancing adherence. How an individual values various outcomes and the self-confidence the person has in the ability to follow through influences the degree to which the individual is likely to adhere

to health behaviors. One of the more common ways of understanding motivation is by considering the cost-benefit ratio that an individual uses in making decisions about health. If the cost of adherence is high, but the expected benefit low, adherence is likely to be poorer than when costs are lower than benefits. It may be possible to improve adherence and support motivation by practicing maintenance skills and building patients' self-confidence, as well as emphasizing the likely positive outcomes of investing behavioral energy in managing lymphedema.

Can Adherence Be Improved?

As should be obvious by now, there are no easy solutions to the problem of adherence. Indeed, a recent review of strategies to improve adherence to medication-taking suggested that although straight-forward interventions have been successful in the short-term, longer term adherence is often not affected. Furthermore, although adherence was sometimes improved, it did not always lead to largely improved medical outcomes. Those interventions that were successful were highly complex, expensive and difficult to implement.

What we can do is pay more attention to the factors that can influence adherence. The goals of management and the intensity of treatment should be negotiated between therapist and patient, and follow-up care should be included in this negotiation so that feedback can be provided. Therapists need to be not only well-trained practitioners, but skilled teachers who can train patients, assess their skills, and assist them in improving their performance without demoralizing them. Patients need not only to have adequate resources for lymphedema management, but may require additional support for co-morbid conditions or to overcome non-supportive family members. Until dismantling studies have been performed, maintenance therapy is likely to remain complex and intense and require a great deal of skill on the part of patients. Given adequate resources and knowledge, maintaining positive interpersonal relationships with patients and supporting their motivation and confi-

dence may be the most important steps in assisting their adherence. It may be best to think of every interaction between practitioner and patient as a teachable moment in which adherence can be specifically assessed and supported.

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A Major Determinant...

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In conclusion, aggressive CDT and strict adherence to a therapy/maintenance program can enable a patient to improve quality of life, as exemplified by the case of Mrs. M. The majority of my patients demonstrate a commitment to controlling their lymphedema. Their inner drive is the backbone of compliance to their program. I believe success begins with a therapist's commitment to the program and the clear communication of that goal to the patient. It is the therapist who must first demonstrate commitment to the patient in order for the patient to develop the necessary commitment to his/her own program. Once the commitment to the program and dramatic results of the treatment is established, the physical work of CDT and adherence to the program will carry the initiative forward with positive outcomes for the patient. □

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