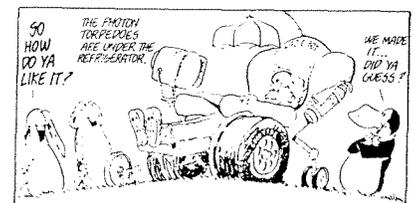
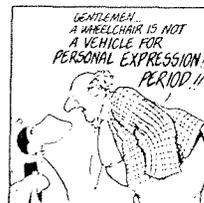
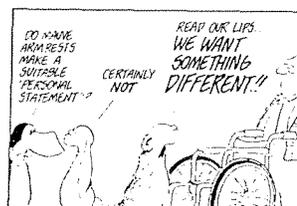
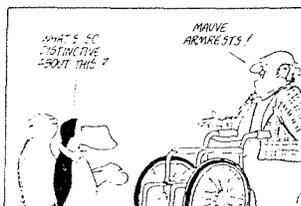


BLOOM COUNTY



Clinical Perspectives on Wheelchair Selection

An Overview . . . with Reflections Past and Present of a Consumer

by Lynn Phillips and Angelo Nicosia

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INTRODUCTION

An estimated 1.2 million Americans use wheelchairs as their primary source of mobility, including nearly 300,000 people with spinal cord injuries, close to a half-million nursing home residents, and those with other mobility-limiting conditions such as muscular dystrophy, multiple sclerosis, and cerebral palsy. To someone who uses a wheelchair all the time, comfort, proper fit, and ease of use is essential and contributes significantly to a sense of independence and the ability to participate as fully as possible in the activities of daily living. If the wheelchair is uncomfortable, is poorly fit to the individual, or is cumbersome to use, it can have serious negative effects on the user's health, mobility, and overall quality of life. In view of the present day variety of options, a wheelchair also can make a distinctly personal statement about the user. Just as people define themselves to others by the clothes they wear or the car they drive, the kind of wheelchair one uses often says something about that person's interests, tastes, and self-image. A wheelchair is not "just" a means for mobility. It is a highly personal device that should be chosen with the utmost care and precision.

WHEELCHAIR SELECTION IN DAYS PAST

The changes in looks and operation of wheelchairs over the past few decades represent a revolution in engineering design. To illustrate this advancement, one only need contrast what it was like for the disabled veterans of World War II. Angelo Nicosia is one of those veterans and shares his first experiences with wheelchairs in the following reflections.

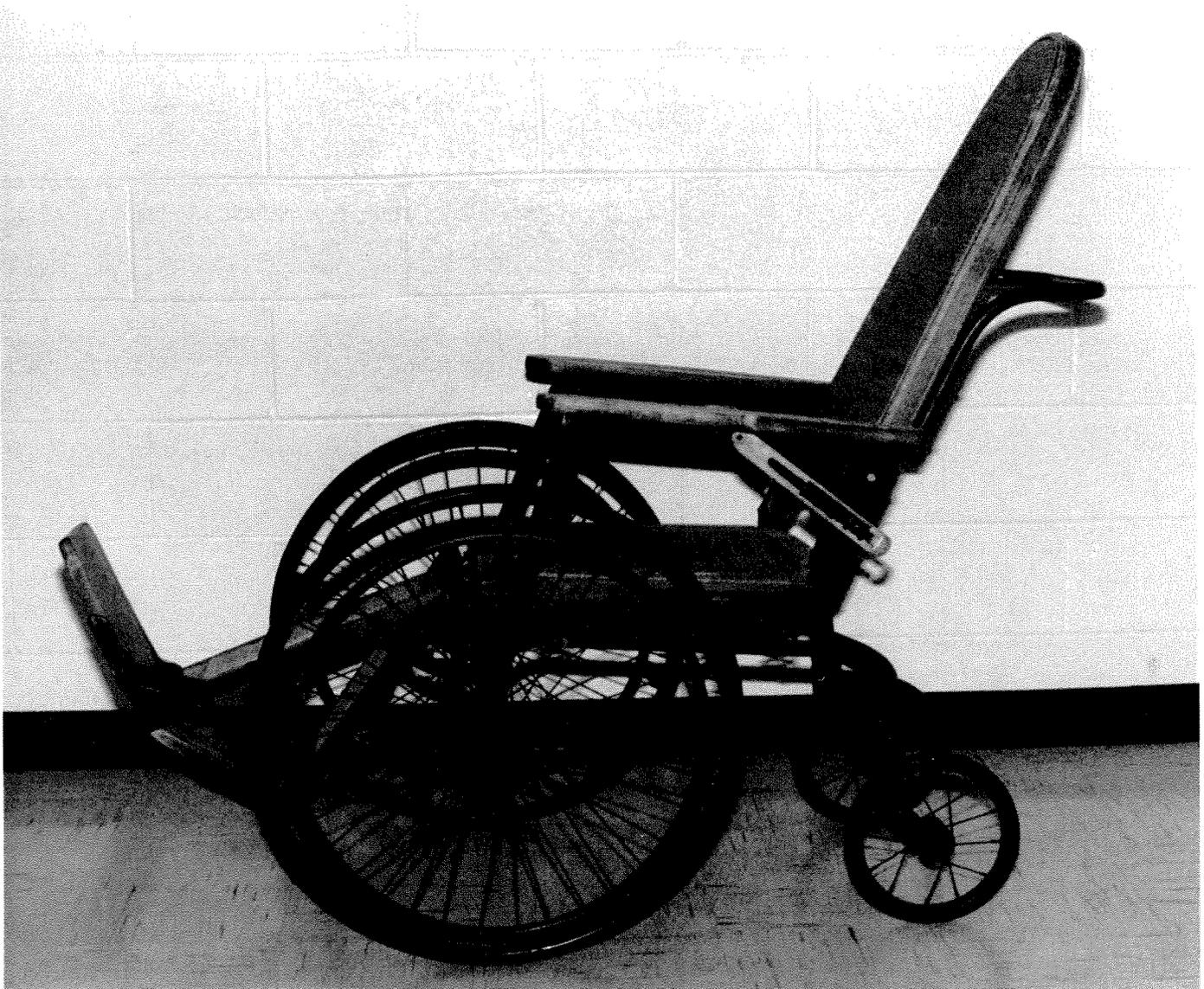
"I recall, back in 1946, the first time I was to get into a wheelchair. My primary physician at the Army hospital where I was brought after my injury was on morning rounds one day after I'd been in the hospital about 2 months and said to all around, 'It's time this patient was out of bed and in a wheelchair.'

"This was good news to me. Either a nurse or a physical therapist then scurried around the ward looking for a patient who was not going to get out of bed that day so I could borrow his wheelchair. They put a pillow on the chair and then picked me up and put me in the wheelchair. Since I didn't have very good balance, they secured me to the chair with a bed sheet.



Figures 1a and 1b.

The front and side views of a wicker wheelchair representative of those used by veterans injured in World War II. The chairs were designed primarily to be pushed by an attendant and were not sized individually for each patient. *(Photos courtesy of Angelo Nicosia)*



“Some of you younger people may not be aware of the type of wheelchair that was commonly used by the military in those days. It had a wicker seat and back and sometimes was called a ‘cane chair.’ It had two large wheels in the front—24-inch wheels, I think—and two casters in the rear (**Figures 1a and 1b**). It was extremely difficult even for a strong paraplegic to propel this kind of chair. I am a C6-7 incomplete quadriplegic, and I could not propel the chair without literally falling out or going over backward.

“It took 3 months for me to receive my new Everest and Jennings 18-inch-width wheelchair. It was all shiny and chrome plated, and I felt

like someone had given me a new Cadillac convertible. Propelling it was a pleasure compared to that old high back wicker chair that I had used in the hospital. Even in my new chair, though, I noticed that my elbows and upper arms got bruised by the armrests as I pushed just the 300 yards to get to therapy. Something obviously wasn’t right with that chair if I kept hurting my arms just by pushing 300 yards, but I didn’t know any better then because I had never used any other regular wheelchair. What I now know is that the chair I was given was too wide for me—at that time I was 5 feet 10 inches tall but weighed only 100 pounds.

“After I was discharged from the Army hospital, I passed on to another branch of the government medical system, the Veterans Administration. I was impressed by all the hustle and bustle at the regional office in New York City: 16 floors of people all working for the benefit of veterans and, since I was a veteran now, they were working for me!

“I met my prosthetic representative, who was a very nice man, as were all people I met at the Veterans Administration. The first thing he asked me was, ‘What can I do for you?’ I asked for a wheelchair to replace the hand-me-down I had been using for a year. He took out his 18-inch ruler, measured my chair sideways, backwards, and I think upside down, and ordered the exact same chair that I had been using.

“When I got my third wheelchair—not until 15 years after my injury—I made some inquiries to bioengineers, a physical therapist, and an occupational therapist about the proper size for my wheelchair. The consensus was that I did have the right size wheelchair. However, by this time I had gone up in weight from 100 to 135 pounds, my neck size had increased from 14 to 17 inches, and I had an enviable 32-inch waist, 40-inch chest, and 33-inch hips. Somehow, though, I still felt that the 18-inch seat was too wide for me.

“On a trip back to my prosthetic representative, I asked if he would allow me to read some of his catalogs on wheelchairs. I found out that at no extra charge I could order a chair with the dimensions that I felt I needed—once I practically signed my life away and that I would accept the order when it arrived! I did it, and I have been using a 16-inch-width chair ever since.

“Those 2 inches have made a tremendous difference: no more sliding around in a chair that’s too wide for me; no more black-and-blue marks on my arms, or pain in my shoulders from holding my arms too far out and up. I am far more comfortable since the wheels are closer to me, and I can propel the chair much more efficiently.

“Thus, I am living proof of some of the problems that can come about when both medical professionals and patients lack the proper knowledge and training to order an appropriate wheelchair.”

WHEELCHAIR SELECTION TODAY

Although wheelchairs today look a lot different from the cane back chairs used in military hospitals just after the second world war, in many cases wheelchair selection is still made by people who have inadequate knowledge about the scope of products and options available to provide for an optimal choice for the user. This is happening for several reasons. In the first place, newly disabled people generally have been thrust very quickly into the population of wheelchair users. Consequently, their knowledge of what kind of chairs are available is limited to whatever they already know about wheelchairs and what they can learn from their therapists and physicians. And, while there are a fair number of knowledgeable people around who do know the wheelchair market, there is no guarantee that a person being prescribed his or her first wheelchair will encounter one of these experts.

It is generally agreed that few practicing therapists and even fewer physicians have had adequate formal preparation in assisting an individual in selecting and then fitting that person with an appropriate wheelchair. For many physical and occupational therapists, training in wheelchair selection and fit has consisted of a single lecture in a course during their schooling. Moreover, because of the rapidly changing nature of the wheelchair market, information in textbooks often is woefully outdated and instructors are ill-prepared to supplement the text with updated information.

In many cases, the most knowledgeable person available on the subject is a salesperson for a particular wheelchair company. However, while this individual may have access to the most up-to-date information, he or she quite naturally will emphasize the philosophy—and products—of his or her own company. And, objectively, it really is not their job to inform and educate consumers about all currently available wheelchairs.

Another difficulty with wheelchair selection today is that, although a wheelchair must be prescribed soon after an individual has become injured—when he/she is still in a hospital setting—it will be used primarily in a home and community environment. As a hospital liaison for Eastern Paralyzed Veterans Associations (EPVA), Mr.

Nicosia sees every day the problems created by this practice combined with the lack of adequate information on the part of prescribers and new users.

“Let me give you a general idea of what has happened to some wheelchair users. A doctor just tells his patient, ‘You’re going to get a wheelchair,’ and writes up a consult for the patient to be evaluated. The doctor is supposed to write the prescription, but frequently he just does not know enough about the individual to do it. So, at least in the VA, the patient will go to a wheelchair evaluation clinic where he is able to discuss what his needs are with a clinician.

“Since the person is usually newly injured and knows little about the subject of wheelchairs, he usually looks at the therapist as the epitome of knowledge. Unfortunately, in many cases, the therapists aren’t very familiar with the new products coming out.

“Sometimes, though, the user will have a notion of the kind of chair he wants from talking with other wheelchair users or from an article he has read. For example, a person may see a new chair or cushion in *Paraplegia News* or *Sports ’n Spokes* and bring the ad in to show the therapist or physician. But if the therapist doesn’t know about it, in a lot of cases he just won’t consider it and might refuse to order it. Or maybe the user says he’d like one of the active or ‘sports’ chairs, but the therapist tries to talk him out of it. In such cases, it’s hard for the individual with little experience with wheelchairs to know what to do.

“I know of still other cases where the physician or therapist will decide something about a patient’s ‘needs’ even if the patient doesn’t agree. For instance, one person I know, a quad who wanted a powered chair that could go at fairly high speeds, was not able to get what he wanted. His physician refused to order it because she felt it was too fast and therefore unsafe. But, what is too fast for one person may be the best pace for another; it’s a very personal, individual decision.

“Such therapists and physicians need to understand that the people who are their patients today are going to have to be, and want to be, independent individuals in a few weeks or months. It can be hard to see a newly injured person that way, but it’s

essential both for proper rehabilitation and for making sure that person gets the right wheelchair.”

Few physicians and therapists are themselves wheelchair users, and therein lies a major problem in wheelchair prescription. It is extremely difficult for a nonuser to understand the nuances of daily wheelchair usage that a user understands intrinsically by being in a chair most of every day. This underscores the need for therapists to listen to and take into account the user’s point of view when making decisions about wheelchair style, special features (such as high speed capabilities on a powered chair), and possible advantages of newer products. (Not coincidentally, many newer products are being developed and marketed by wheelchair users themselves.)

No place, though, is the perspective of the user as important as in the decisions about “proper” fit. For many individuals the standard measurements and fitting practices are not going to be appropriate. The rules that a therapist or physician learns about how high a back “should” be, or whether or not a chair “should” have armrests, or how high off the floor a wheelchair “should” stand, often need to be modified or even discarded completely in order to best meet individual needs. The only way to gain this kind of specific knowledge that meet the variety of a patient’s needs and abilities is to listen to him expressing them and by paying attention to what is said by experienced wheelchair users.

For many years the standard wheelchair was 18 inches wide for an adult; yet as Mr. Nicosia described earlier, he found it more comfortable and efficient to use a chair with a seat 16 inches wide, even though no one seeing him would describe his build as slight or small. From the “standard” point of view Mr. Nicosia’s chair would be considered too narrow; but, in fact, the narrower seat means he can propel the chair more easily because he does not have to reach out so far for the wheels.

It is also common practice to allow for an extra inch on each side of the buttocks “for bulky clothing,” or because the therapists assume that the individual will be gaining weight once he or she gets home, or for any one of several other imagined reasons. For many individuals, however, those extra 2 inches mean that they will have to hold their arms

out farther than necessary to propel the chair. In some cases it will increase the tendency to lean over to one side, which can lead eventually to curvature of the spine. It is necessary to fit the user for the wheelchair he needs at the present time, not for the one he "might" need in the future.

Mr. Nicosia has noticed other areas in which common prescribing practices actually serve to limit function, and has made the following observations.

"Even though I'm a quad, I don't use armrests. Almost every therapist I know includes armrests automatically when ordering a chair for a quadriplegic patient, but for me they just get in the way. What are armrests for, anyway? I can rest my hands in my lap or on a table, and I can get closer to the table when I don't have armrests getting in the way. A lot of people do 'push-ups' on armrests, but manufacturers say you shouldn't put that much weight on them; and, anyway, I do push-ups from the seat of my chair with no difficulty. So I really wish people who are prescribing wheelchairs would reconsider why they are including armrests with almost every one they prescribe.

Another thing that I personally like is a low back. Most books on prescribing chairs say that the back should come to about the level of your armpit, but mine comes up only 14 inches from my seat. With the lower back I can turn around in my chair, reach for things behind me, and in general have a lot more freedom to maneuver than I did when I had the standard highback chair. While it's generally true that most quads will probably need the higher backs, as in my case, there are going to be exceptions, and people prescribing chairs have to become more aware of these exceptions."

Proper seating is an essential consideration in wheelchair selection. This is one area, too, where the potential user is at a disadvantage. Although wheelchairs and seating systems are actually distinct products with different purposes, they work as a unit in providing the user with a method of mobility. Unfortunately, oftentimes the wheelchair is selected first and separate from the seating system—or vice versa. However, if they are not selected at the same time the height at which the user actually will be sitting can be adversely affected, i.e., by a seat that is too low for a cushion that is

relatively thin, or by a high rigid cushion combined with a high seat.

Although a user can determine fairly quickly whether or not a particular cushion provides adequate postural support and comfort, he has virtually no concept of what kinds of cushions will most adequately relieve pressure on the buttocks. However, he is not alone in this matter because there is little agreement among clinicians and researchers on the "best" way to relieve pressure. The major cushion types—ROHO, VASIO-PARA, Foam-In-Place, Jay, and the standard polyurethane foam or gel cushions—emphasize different properties and different designs for relief of pressure. For a consumer, this is confusing and most often leaves the full responsibility for this decision on the prescribing physician or clinician. Thus, it is very important that practitioners become familiar with all the available seating systems in order to make the best possible choice for each individual wheelchair prescription.

TOWARD WHEELCHAIR SELECTION IN THE FUTURE

Despite improvements over the years and an increasing number of options, there still is a significant need for improvement in the process of selecting mobility systems both for newly injured and experienced users. The most serious problem with the process of selection today still seems to be the lack of active involvement of the user himself in the selection process. The individual who will be using the wheelchair on a day-to-day basis outside the hospital is the only person who knows what kind of life he will be leading, what his own personal likes and dislikes about wheelchairs might be, and what he wants the chair to say about himself. As therapists and physicians become more aware of the importance of involving the user in making decisions about what kind of chair is most appropriate, the rate of successful prescriptions will increase.

Another difficulty with current practice is the tendency to prescribe chairs generically, using one set of standard rules that do not necessarily fit every individual. It is imperative to remember that people come in all shapes and sizes, and that the emphasis

should be on fitting the wheelchair to the person, not the other way around.

It makes sense that wheelchairs and seating systems should be selected in a coordinated process, since they must function as a unit for the user. Clinicians need to become more aware of the variety of products and combinations available. To remain current in this field, it is important to keep informed about new product development and research evaluating the products on the market. Excellent sources of information are experienced users and periodicals aimed toward users, such as *Paraplegia News*, *Accent on Living*, and *Sports 'N Spokes*.

CONCLUSION

Clinicians and users alike need to be made aware that the solution to the problem of developing a better process for prescribing a wheelchair system involves attention to a number of related issues. In wheelchair conferences and other meetings we have heard many people advocate the need for a "trained wheelchairist," a designation that would certify those who assist individuals in choosing wheelchairs with a certain standard of knowledge and competence in the field. Ideally, a certification process for wheelchair selection personnel would lead to an increase in the number of properly fitted and properly prescribed wheelchairs.

In the meantime, it is essential that physicians who prescribe chairs and therapists who fit and select chairs for their patients become better informed about the options available and about the intricacies of proper measurement for individual

users. This might be accomplished by organized training teams who present workshops on wheelchair selection throughout the country. Such teams would include at least one person who is a wheelchair user to emphasize the value of listening to the user's perspective when selecting a wheelchair.

Standardizing methods for describing and disseminating information on current wheelchair products is also important. The RESNA/ANSI Technical Advisory Group (TAG) on wheelchair standards has developed standard methods for disclosing information about wheelchairs, while working on domestic and international standards for wheelchairs. Wheelchair manufacturers are encouraged to disclose information about their products in the formats that are being developed so that product-by-product comparison will become less subjective and more easily accomplished. We also hope that the information on these products can then be put into a computer program accessible to prescribers throughout the country. Such standardization should enable every facility that prescribes wheelchairs to have up-to-date, balanced information about the current wheelchair market.

Finally, we hope to see continuing improvement in the range and quality of options available to wheelchair users. Over the past 5 to 10 years, the wheelchair market has become much more competitive and dynamic. This has encouraged new companies to introduce lighter, faster, and less expensive chairs. Moreover, many wheelchair users have marketed products on their own. This trend has significantly expanded the choices available to wheelchair users, and we can only hope that it continues.