Assistive Technology and the Newly Disabled Adult: Adaptation to Wheelchair Use

Pearl Sarah Bates, Jean Cole Spencer, Mary Ellen Young, Diana Hopkins Rintala

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A naturalistic, ethnographic, phenomenological study of adaptation to wheelchair use was conducted with one key informant, a 30-year-old white man with acquired paraplegia who was undergoing acute rehabilitation. Primary staff members served as additional informants. It was found that adaptation to wheelchair use had both pragmatic and emotional components. The latter appeared in alternating phases of resistance and neutrality or detente. Therapist and patient had conflicting goals relative to wheelchair use, which occasioned considerable friction. The patient's initial attitudes regarding wheelchairs were prejudicial, which hampered his ability to see the chair as a useful tool for mobility and independence. Successful pragmatic adaptation hinged in part on emotional acceptance of the wheelchair.

After an acute spinal cord injury, formerly nondisabled persons find themselves confronted with wheelchairs. How, while facing the many other challenges inherent in new disability, can they incorporate such unwelcome devices into their lives?

Literature Review

Such persons may encounter their first wheelchair already burdened with the mixed or negative views shown by research to be prevalent in contemporary society. The existence, among persons without disabilities, of prejudice against wheelchairs and their riders has been well documented in the literature of rehabilitation psychology and counseling (Fewster, 1990; Fichten & Amsel, 1986, 1988; Fichten, Robillard, Tagalakis, & Amsel, 1991; Giancoli & Neimeyer, 1983; Phillips, 1990; Wright, 1983). Persons without disabilities show symptoms of social strain around persons in wheelchairs, including short interaction times, excessive physical distance, and negative self-talk (Dawson, 1990; Fichten & Amsel, 1988; Fichten et al., 1991; Hastorf, Wildfogel, & Cassman, 1979; Kleck, 1968). Wheelchairs are also viewed simply as tools, however. Bates (1992) found that rehabilitation engineers viewed wheelchairs and other equipment as partial technological solutions to what they designated "the predicament" (p. 81) of paralysis. Campbell and Ross (1990) claimed that wheelchairs are merely "practical solutions to a practical problem" (p. 23). Positive prejudices, such as the view that wheelchair users are heroes, have also been found (Christman & Slaten, 1991). However, positive prejudice may present as great a social impediment as negative prejudice (Pedretti & Zoltan, 1990; Wright, 1983).

Persons without disabilities are not alone in these conflicting views about wheelchair use: Wheelchairs have received mixed ratings from their users as well (Antler, Lee, Zaretsky, Penezik, & Halberstam, 1969; Campbell & Ross, 1990). Persons with mild disabilities viewed the wheelchair positively, seeing it as a temporary solution to a temporary problem. Persons without disabilities and persons with severe disabilities held the most negative attitudes toward wheelchairs (Antler et al., 1969). Zernitsky-Shurka (1987) and Fichten et al. (1991) found that wheelchair users preferred the company of persons without disabilities to that of other wheelchair users.

In most of the above studies, the researchers defined as their independent variable the presence of a person in a wheelchair, rather than simply the presence of a person with a mobility impairment. In double-blind studies, subjects were set up to encounter and respond to persons in wheelchairs. In some studies, the wheelchair-using accomplice was actually a nondisabled actor (Hastorf et al., 1979; Zernitsky-Shurka, 1987). Although this may seem a minor point, it indicates that the subjects responding to the wheelchair users in these studies were unable to tell that the accomplices did not actually need the wheel-
chairs in which they rode. In their study of peer preferences among college students, Fichten et al. (1991) incorporated four categories of subjects: visually impaired, bearing impaired, able-bodied, and wheelchair user. It was not mentioned that wheelchair user is not an equivalent term to visually impaired or bearing impaired. The appropriate parallel term would have been mobility impaired. Only in the case of persons who use wheelchairs is the device itself regarded as a disability. This attitude is not unprecedented in the history of assistive devices: as Wright (1982) noted, the wearing of eyeglasses was once considered just cause for social and sexual distancing, much as a wheelchair is in these times. Wright recalled Dorothy Parker’s observation from 1927, “Men seldom make passes at girls who wear glasses” (cited in Bartlett, 1980, p. 827). It is the chair to which the subjects in the above-mentioned studies are expected to—and do—react. This is a powerful statement indicating the status of the wheelchair as the symbol of disability. This status is reinforced by the universal symbol of accessibility, a blue abstract wheelchair with rider on a white field.

New wheelchair users find themselves facing the architectural and attitudinal barriers of society, while still struggling to reorganize their own attitudes. Major psychosocial changes, in areas ranging from body image to vocational role, take place during the rehabilitation process. The implications of these emotional and attitudinal issues for either the technology provider or the technology consumer have been little discussed in the professional literature. The consumer literature, in contrast, is replete with critiques of the equipment provision system (e.g., Shreve, 1991).

The reshaping of one’s daily activities and environment so as to negotiate life in a wheelchair—what might be termed pragmatic adaptation—appears to level off within the first year after injury (Nort-Baker & Willems, 1978). Emotional adaptation to the use of a wheelchair seems to be a lengthier process. Avillion (1986) found that those with less than 6 years of wheelchair use had lower self-esteem than those with more than 6 years. Patrick (1984) found that veteran wheelchair athletes displayed positive self-concept and acceptance of disability when compared with novice wheelchair athletes.

Importance of the Study

Although occupational therapists often find themselves in the role of equipment providers, occupational therapy theory does not generally address questions of why or whether to prescribe equipment. The fairly extensive occupational therapy literature pertaining to adaptive equipment appears to focus almost exclusively on application. Nor is there much clinical research that directly relates equipment provision to functional outcomes. Therefore, basic descriptive research addressing the equipment provision process is needed. Qualitative research can provide raw materials for theory building and for generation of testable hypotheses for future quantitative studies.

Method

The use of disability ethnography in occupational therapy has been advocated by Krefting (1989). Intensive study of representative cases has also been supported by Heine-mann and Shontz (1984):

Representative case research is based on the proposition that when studying individuals as complex psychological structures, greater understanding results from having data on many variables, collected from a few carefully chosen persons, than from having the same amount of data on only a few variables, collected from many persons who are otherwise unknown. (p. 5)

This view parallels Krefting’s (1991) argument that applicability, not generalizability, is the goal of qualitative research. The researcher is expected to provide enough detail to allow the reader to determine whether or not the results of the research apply to a given clinical situation. This method of research application parallels occupational therapy clinical reasoning, in which meaning is derived and applied through the use of narrative (Mattingly, 1991).

This article is based on a larger holistic, naturalistic, ethnographic study of adaptive processes after spinal cord injury. The focus of the larger study was a phenomenological attempt to understand the experience of spinal cord injury rehabilitation from the patient’s point of view. A single participant with a traumatically acquired spinal cord injury agreed to serve as the key informant. Russell (a self-selected pseudonym), a 30-year-old white man, had been employed as a welder and rigger. He was divorced and had recently become the custodial parent of his 10-year-old son. While rigging ceiling lights for a concert, Russell fell; he incurred a spinal cord injury at the 12th thoracic vertebra and fractures of the left wrist and elbow.

Russell was interviewed daily during most of his inpatient rehabilitation period, which lasted approximately 4 months and yielded 70 interviews. He ceased participation in the study approximately 2 weeks before his discharge from the rehabilitation hospital. A single follow-up interview was conducted 9 months after injury.

Russell’s primary occupational therapist, physical therapist, nurse clinician, and social worker filled out daily forms cataloging treatment activities, setting, people present. Russell’s reactions to treatment, and the staff member’s impressions of Russell on that day. In addition, these staff members were interviewed weekly. Some family members also granted interviews.

All interviews were open-ended and were taped and transcribed verbatim for analysis. Field notes were collected based on interviews, rounds, therapy sessions, and case conferences. For purposes of the present paper, the

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The initial goals of the therapist included “Initiate sitting.” Twenty-five days after his injury, Russell was transported on a stretcher to a freestanding rehabilitation center. His initial goals included independent mobility at the wheelchair level and independent transfers. His occupational therapy initial assessment quoted Russell’s own goal as “To get me in a wheelchair and to get me out of here.”

The initial goals of the therapist included “Initiate sitting program” and “Improve sitting time to 4 hr pm.”

On his third day in rehabilitation, Russell was issued a high back recliner chair with head-rest and fixed leg rests, on loan from the occupational therapy department. It had standard pushrim, which Russell was unable to propel because of his left upper extremity fractures. As his body jacket was not fitting properly, his first sitting was postponed until the following day. He expressed anxiety to begin therapy:

Russell: I’m ready to get started . . . Working my legs, getting me out of this bed, getting me moving around a little bit.

Interviewer: Uh huh. And then you’ll feel like you’re doing something.

Russell: Yeah, I might feel like wanting to live again. [Explosive], the way they got me now [unable to get out of bed] I feel useless, worthless. And it’s driving me crazy just sitting here.

On his fourth day in rehabilitation, Russell was lifted into the chair by three nurses, a process he described as “not fun.” He had a disturbing sense of loss of control over parts of his body, describing his legs as “weird” and “useless.” He continued to be motivated to use the wheelchair and asked practical questions, such as whether or not one could get pressure sores sitting down. He quickly learned his body jacket precautions and echoed the aids if they did not follow these exactly during transfers. Russell spent his seventh day of rehabilitation in bed because the body jacket again needed adjustment. His comments give the first indication that his own goals differed from those of his occupational therapist. Although the initial assessment gave the impression that Russell and his therapist shared similar goals (“Get me in a wheelchair” and “Initiate sitting program”), this appearance was deceptive. The occupational therapist apparently intended to help Russell make a smooth transition to long-term wheelchair use. Russell’s sole interest in the chair was as a means of getting to physical therapy, where he planned on learning to walk again:

I told [the physical therapist] well, as long as I can eventually . . . be able to walk . . . she still won’t say I’ll walk. I said I’m gonna make you say it one of these times, you know. And she goes, I can’t. I said, well, there’s all kinds of different ways of walking, you know, there’s walking with crutches, I said that’d be great. You, you get me on crutches, and I said you know, I’ll have to work them legs and keep on working ’em so they will have to work eventually. So that’s fine. Get me on crutches. And she goes, yeah, you’re never gonna give up are you, I said, nah.

By day 9, Russell began to rebel against the sitting schedule (1 hr, three times a day) prescribed by his occupational therapist. He stated that he had already been up for two 2-hr stretches, once in the morning and once in the afternoon. He refused to get up the third time in the evening, asserting defiantly: “They make it sound as if I don’t have a choice, but I’ll tell them I’m not going to get up.”

The weekly occupational therapy note from day 10 recorded that a progressive sitting program had been initiated, and that the patient was sitting with the backrest adjusted to 70° for 1 hr, three times daily, on a foam cushion. The new short-term goal was upgraded to sitting at 80° for 2 hr at a stretch. This meant spending 6 hr a day in a chair that he was unable to propel. Russell expressed considerable frustration with this plan:

I hate that time then because I can’t do nothing. They might as well stick me in a damn closet. Can’t move, can’t do nothing . . . all you can do is sit there and think how helpless you are.

He was told that when he could tolerate sitting at 90° he would be provided with a one-arm drive chair that he could propel independently. This news made the sitting schedule somewhat more meaningful to him. However, when he achieved this goal on day 11, the new chair was not immediately forthcoming. According to a later interview with Russell’s occupational therapist, the chair had to be ordered from the facility warehouse due to the unusual need for a one-arm drive on the extra-tall chair required to accommodate Russell’s height of more than 6 ft. At this delay, Russell again became frustrated and rebellious, asserting angrily that “I may be stuck with that piece of junk till I go on home. . . . Piece of junk from World War I.”

Russell began to allude to purposeful sabotage of his sitting schedule, indicating that he had “been cheating, for a while,” not staying up as long as he was expected to. He made it clear that his cooperation with the schedule was contingent on having a chair that met his functional goals as he defined them:
On day 17, the occupational therapy chart notes reported that the patient was sitting for 2 hr three times daily, and that he "will be issued a one-arm drive wheelchair." The note also reported that the patient was using his right hand to propel the existing wheelchair "with moderate difficulty." The researchers observed rounds that day, where the sitting schedule was advanced to 2½ hr, three times daily. The following day, the interviewer found Russell quite angry about this development:

Interviewer: I see your schedule’s wiped off. Are you getting a new one? Or you just didn’t need it . . .

Russell: It’s in the trash right now. . . . Cause I told them I wasn’t going to be the one to get a new chair. . . . I tell you what. I’d like to get a cutting torch and cut this sucker up. I hate this chair.

By day 19, Russell was in too negative a mood to cooperate with therapy:

Tired of fighting with the damn thing [the chair], so I just said, hell with it. Then uh, [the] OT, he came in here and took me out and walked me around outside. I needed that.

Russell’s primary occupational therapist described the same event in the next interview. He characterized Russell’s mood as irritable, depressed, angry, talkative, and tearful. He ascribed this state to Russell’s feeling out of control with a wheelchair he could not propel. However, he believed that Russell’s therapy was going well overall and that they had good communication.

Russell’s extreme frustration with his inability to propel the chair poses an interesting quandary. He complained repeatedly that he did not want to get up in a chair and be stuck in one place, yet he was willing to lie in bed, where he was also stuck in one place. Because what he typically did in bed was to watch television or talk, he could have participated in the same activities while seated in WCI. He did not indicate that sitting caused him any physical discomfort; nonetheless, it was unacceptable to him.

One possible interpretation of Russell’s attitude is that he may have been expressing a covert prejudice against wheelchairs per se, and a consequent reluctance to admit that he needed one. The societal prevalence of prejudices regarding wheelchairs, as well as Russell’s own later comments regarding not wanting “to be stuck in a wheelchair” or preferring death to being “crippled,” lend weight to this interpretation.

Some resistance may also have derived from Russell’s attempts to deal with the emotional effect of his disability by displacing feelings about his paralysis onto the chair itself. Control was an important issue to Russell, as both he and his occupational therapist pointed out. A newly paralyzed person in a hospital loses control over many aspects of his or her life—not only over limbs, but also over the daily schedule, including times for therapies, sleep, waking, meals, and even elimination needs. This situation can be nearly insupportable to an independent adult such as Russell (Bates, Spencer, Young, & Rintala, 1993). Russell had also lost control of other important aspects of his life, including the care of his young son. The 10-year-old boy had been returned temporarily to the custody of an irresponsible mother who used drugs, a situation that occasioned Russell immeasurable stress. Russell’s family members had taken charge of his finances, his apartment, and his vehicles. To be saddled with a wheelchair he also could not control was perhaps the last straw. The wheelchair that he could not wheel appears to have become for a time the very emblem of impotency: “All you can do is . . . think how helpless you are.” It is no wonder that he wanted to cut it up with a torch.

A third interpretation of Russell’s frustration with the immobile wheelchair and the time he was required to spend in it for his progressive sitting program has to do with the core of occupational therapy: the concept of purposeful activity. The activity of sitting was seen as purposeful by the occupational therapist because he believed that Russell would be a long-term wheelchair user. In his view, increasing Russell’s sitting tolerance was preliminary to rebuilding functional independence at the wheelchair level. Russell, however, was not ready to accept the idea that he would be a long-term wheelchair user. To him, the chair was a means to a different end, to get to physical therapy and learn how to walk again. Simply increasing sitting tolerance was an activity without a purpose, a meaningless exercise in frustration. He had cooperated relatively willingly so long as he had the incentive that he would be issued a chair he could propel once he was able to sit at 90°. When he achieved this goal and the one-arm drive chair was not immediately forthcoming, he became increasingly uncooperative with the sitting program.

On day 22, 11 days after achieving a 90° sitting posture, Russell received his one-arm drive chair. He immediately put the chair to use:

I went to PT in it. Well, now that I got my chair, I [have] to follow a [sitting] schedule . . . I got no excuses now.

After provision of the one-arm drive chair, his war against wheelchairs entered into a period of neutrality which we labeled détente: He gave no indication of liking or even accepting the chair, but, for a time, hostilities ceased. He was beginning to stand in the standing frame in physical therapy, which renewed his hope of walking. He occasionally mentioned his new chair, but only in passing. The tone of these comments was neutral, in marked contrast to his rages regarding the first chair:

Interviewer: So, what did you do today, besides go to PT?

Russell: Oh, just got in my chair and rod around a little bit. Not much of anything.
Field notes from this period document that he was sometimes sitting in the wheelchair for interviews, in contrast to his previous pattern of lying in bed. The next interview with the occupational therapist, on day 31, described Russell’s increased independence and improved attitude:

He’s doing a lot better. I feel that he appears to be more cheerful, talkative... We continue to emphasize... activities to improve his independent living skills, such as propelling his one-arm drive wheelchair, which he has made tremendous strides in... he’s manipulating it very well, and he feels a lot more comfortable now that he is in control and being able to go places.

By roughly one month after admission to rehabilitation (day 33), Russell had lost interest in either fighting against or complying with his sitting schedule. It can be seen from his careless attitude that his détente with the chair extended to include the schedule:

I don’t go by that. I sit. I sit more, sometimes, and sometimes I don’t sit as long.

He also began to look beyond his own viewpoint to recognize the concerns of other people. He recounted feeling sorry for the wife of his roommate, and described an occasion when he had lectured the roommate on this topic:

I explained it to him one night. I said “Man...you know, for one... she’s going through a lot of changes with you being in a wheelchair, and for two, you know she’s pregnant... her body’s going through a bunch of changes. Too. And you know, her head, she’s going, you know, hopefully, she doesn’t lose it. So...you got to take it easy on her, and help her out.” He goes, “Yeah, I didn’t think of that.” I said, “Well, you better think of it, cause you’re not the only one that’s losing from all this (expletive) you know.”

Russell was not ready, however, to apply this insight to his own life. The same interview continues:

Interviewer: So, how are your family members holding up under all this? Is anybody taking it harder than the others? Or, who is it hardest on?

Russell: I’m the one in the wheelchair.

This reaction may have been related to the beginnings of a realization that a wheelchair might be a permanent fixture in his life. Despite his ongoing hope of walking, fueled by that fact that his paralysis was incomplete, he began to recognize that he might not recover all of his previous abilities. He mentioned that, before being injured, he had been saving to buy a house. He stated that now “I gotta find a house with a wheelchair. Accessible.” Although the wheelchair was no longer a topic of daily discussion as it had been before his receiving the second chair, these gradual realizations continued throughout his second month of rehabilitation. On day 40, he began to talk about some of the social implications of using a wheelchair. It was evident that he still held many of the prejudicial attitudes typical of persons without disabilities (c.f. Wright, 1983):

Russell: My coworker was surprised I didn’t ask about sex. That’s the least of my worries right now... First you gotta have a girlfriend before you start worrying about that. (laughs)

Interviewer: Well, you might have a girlfriend someday.

Russell: Not if I’m in a wheelchair.

Interviewer: What makes you say that?

Russell: I just know. You know, how often do you get out when you’re in a wheelchair?

Interviewer: Some people do. They get out a lot.

Russell: Well, if you look around, you don’t really see any wheelchairs all that often. As many people as I seem go, come and go in this place. they should be all over, all over the place.

Interviewer: Yeah.

Russell: You don’t see ’em often. Once in a long while you see ’em... seems kinda strange. I don’t want to be stuck in a wheelchair.

Interviewer: Yeah.

Russell: You know, I always told myself, if I was ever gonna get crippled, I’d rather be dead. I don’t know how it is possible that I still think that, if I was gonna be crippled, I’d rather be dead.

With this assertion, Russell renewed his war against wheelchairs. The period of détente was over. On day 43, he refused to participate in a physical therapy class on how to go down steps in a wheelchair. On day 49, he walked for the first time in parallel bars, supported by his physical therapist, but the elation of that moment passed quickly. As his awareness of the potential for long-term wheelchair use grew, his depression reappeared. He asserted that “When you’re in a chair, you learn to give up.” His plans for life after discharge consisted of retreating into the world. He explained that he would be unable to get into the apartment where he had lived with a cousin before his injury. His planned solution was to get into the apartment once, by scooting on his rear up the stairs, have his cousins pull the wheelchair upstairs for him, and never go out again:

Well, once I’m up there, I don’t have to go out. They can go get groceries and everything... I really don’t have to go out for nothing.

Russell’s occupational therapist reported that Russell was making functional use of his improving wheelchair skills, including going to the cafeteria and carrying a tray of food on his knees. However, he again expressed concerns regarding Russell’s emotional acceptance of the wheelchair:

I had made the recommendation that he go this Thursday to the baseball game, and he refused, and I’ve been encouraging him to go out with the other patients, so that he’d be able to adapt and reintegrate back into the community. I say, You need to do this while you’re in the hospital, so it won’t be a shock once you get out there. At least you’ll have other peers that are in wheelchairs, and you’ll be able to relate and get experience, and interact with other people.” And he says, “Well, in the past, I always worked and I didn’t have time to go out.” And he says, “The only time I’ll need to go out is, like, going to the grocery store.” and my concern is Russell not getting out into the community once he’s released...
from the hospital, after our conversation yesterday. So I'm going to continue to encourage him to participate in out-trips, and get out and meet people.

The occupational therapist's weekly progress note dated the next day indicated that Russell was able to sit for 4 hr at 90°, the initial goal set by the therapist. Russell's walking also continued to improve, and he entered into another period of détente with the wheelchair. Russell reported on the only group out-trip in which he consented — a trip with a male recreation therapist to a local toless bar. He discussed having his truck parked outside the rehabilitation hospital as an "escape vehicle"—although he could not yet drive. On day 67, he reported that his stay in the rehabilitation facility would be extended by 2 months because he was getting so much return of function in his legs.

During his third month of rehabilitation, Russell's participation in the study was sporadic. On day 81, Russell stated in his interview that he had received his leg braces from the prosthetics department and that he had also gotten a new loaner chair on the previous day. This third wheelchair had two standard pushrims that he could now operate after the healing of his left arm fractures. The occupational therapist's note on that day reported that Russell had used both hands to propel this chair on linoleum and carpeted surfaces.

Russell was matter-of-fact in his remarks about the third chair. His second détente continued. His interviews during that period focused on walking. He had achieved not only the therapist's goal for wheelchair use, but also his own: He could propel himself to physical therapy independently. It was apparent from his comments about going home with braces and a walker that he had returned to the view that the wheelchair was a temporary measure. As such, it had no particular emotional effect on him. It was, for the moment, a "practical solution to a practical problem" (Campbell & Ross, 1990, p. 23). When asked by the researchers why he was not going out on pass more often, he denied any discomfort with using a wheelchair in the community, merely stating that it was "more of a hassle."

As Russell began to anticipate his discharge from rehabilitation, he expressed concerns regarding environmental accessibility. His second period of détente in "the war against the chair" began to be disturbed by periodic realizations of what was ahead of him. From day 93 on, most of his comments about the wheelchair centered on access. The problems of pragmatic adaptation were becoming apparent to him:

Russell: Kinda scary. But, kinda can't wait to get out of here.

Interviewer: What seems kinda scary about it?

Russell: Well, there [outside of the rehabilitation facility] they're just not prepared for wheelchairs to be all over the place. Here they are.

He had begun to arrange for a downstairs apartment, but reiterated his old theme of withdrawal:

Russell: I don't plan on going anywhere for a long time. Stay home. ... Can't really get around, so I just get to wait until my leg gets stronger. They should be sending me home with a walker and all that [explosive].

His statement that he "can't really get around," when his wheelchair mobility appeared to be excellent, seems to indicate that "getting around" to him still meant walking. Despite 3 full months of wheelchair use and opportunities to observe others in wheelchairs, he still had not accepted the idea that he was able to "get around" in a chair.

On day 96, he related that walking with crutches was hard. He stated for the first time that he would be going home with a wheelchair, not merely crutches or a walker, as he had claimed earlier:

I'll be using my wheelchair a lot when I leave here. ... And, uh, I'll just be walking a little cause it [left leg] gets tired real easy. ... Well, they already told me I was going home with a wheelchair. ... They always give you a darker, too, until the wheelchair comes in.

Nonetheless, the realizations dawning on him were still interspersed with periods of détente:

Russell: If we move downstairs, it'll be nice, 'cause we'll have our own little patio in back. ... Get out there and sit outside for a while.

Interviewer: Will you be able to get in and out by yourself?

Russell: I'm not sure. I'll probably have to make a little ramp. ... That won't be hard.

Although the staff members had believed from the outset that he would ultimately function primarily at a wheelchair level, as documented in the occupational therapy initial assessment and in the physician's history and physical examination report, it appears that this realization came to Russell very slowly. After 3 months of wheelchair use, he was barely ready to accept the idea of going home in a chair instead of walking. He was still far from ready for the concept of long-term wheelchair use. It may have been more difficult for him to accept this concept because he was able to walk short distances with crutches and braces. On day 99, he gave his last interview. The realization that he would not walk out of the rehabilitation center hit hard. His second period of détente with the wheelchair was clearly at an end. He was angry, frustrated, and depressed:

Russell: I'm so sick and tired of this [explosive] place. ... Yeah, it's like graduation. You get your diploma and get out, and then find out the last day you don't get it.

Interviewer: You mean you thought you'd be walking out ... Russell: Yeah. ... Just comes to, you know ... I'm gonna have to be off my feet, get my feet held up, or I can walk and [explosive] won't happen. ... So I might as well stay in the [explosive] chair.

After this interview, Russell ceased participation in the research project, stating that he had "too much on
[his] mind right now.” Occupational therapy documentation did not mention wheelchairs again until day 112, when it was reported that Russell “participated in wheelchair clinic, and was shown options for his specific needs.” It was recommended that he order a lightweight manual wheelchair, extra-tall to accommodate his height, along with standard accessories such as cushion and backpack “to facilitate patient’s functional activities: i.e., wheelchair functional mobility in the home and community environment, hygiene, feeding, etc.”

On day 115, the therapist reported that Russell was provided with his fourth wheelchair, an inexpensive rental chair, which he was to take home and use until his purchased chair arrived. Because neither he nor his occupational therapist was interviewed between day 99 and his discharge on day 116, his reactions to the ordering of his purchased wheelchair and to receiving the rental chair are unknown. A field note based on a brief contact with him on his discharge date recorded that “He seemed to accept it okay.” The physician’s discharge summary reported that

He was independent in pressure release, positioning in wheelchair, positioning of cushion, wheelchair parts, terrain with even and uneven surfaces, ramps, [and] doors and required minimal assistance with curbs. Was dependent in managing stairs from a wheelchair, [required] maximal assistance loading wheelchair in and out of car, demonstrated proper falling technique and was dependent in picking up objects from the floor. Most of these levels of assistance related to body jacket precautions.

The occupational therapist’s discharge summary, day 116, lists follow-up plans, including “to assess wheelchair upon arrival from vendor and contact patient for delivery.”

A follow-up interview conducted during his second rehabilitation stay, 9 months after injury, revealed that Russell continued to struggle with adaptation to wheelchair use. On the one hand, he believed himself to be competent in the use of a wheelchair:

They said, you know, when I came in here, I’m gonna do my advanced wheelchair skills. I says, Like what? Oh, going up and down curbs and all that. I know how to do that. I’ve been here for a couple of months, man, I’ve already taken care of that stuff.

On the other hand, he continued to hope that he would walk again. He told the interviewer stories of people who had late return of function. He related that he had isolated himself at home, living out the view expressed in earlier interviews that people in wheelchairs don’t get out much:

We don’t really go anywhere. I guess that’s why I don’t know anybody here [in the city].

Nonetheless, he was making progress toward moving out of his isolation. He had purchased a van the previous week and was working on getting it insured. He stated that he did not know why he had waited so long to do so. He spoke matter-of-factly about his wheelchair when discussing it directly. He appeared to have entered a third period of détente with the wheelchair. This détente differed greatly from those earlier in that it did not appear to be based on the view that the wheelchair was merely a temporary fixture in his life. The fact that he had conceived and carried out the plan of acquiring a vehicle in which he would be independently mobile while still using a wheelchair also indicates a change of attitude regarding the use of a wheelchair in public. It was no longer “too much of a hassle.” This changed attitude allowed him to progress toward greater pragmatic adaptation. He was ready, at that point, to consider becoming more involved with life outside the narrow round of his apartment and outpatient therapies.

Conclusion

Clinicians may benefit from recognition that the process of adaptation to wheelchair use takes place over a period of years. It appears to have several components, including pragmatic adaptation, a reorganizing of one’s life to accommodate a wheelchair as smoothly as possible. Pragmatic adaptation began for Russell the first time he was lifted into a wheelchair and began purposefully to educate himself about pressure sores and safe transfers. Nine months after injury, he had taught himself the skills he so adamantly refused to learn in therapy, such as traversing curbs in his chair. Many aspects of his life were back in order: he had accessible housing, a vehicle, and, perhaps most important, had regained custody of his son. He had not, however, returned to work, refusing his former employer’s offer of a desk job as “charity.”

Emotional adaptation, of which only the initial stages are addressed in the present study, occurs over a longer time period than the initial pragmatic adaptation. Russell’s emotional adaptation to wheelchair use swung like a pendulum between angry depression and a comparatively neutral state.

As providers of rehabilitation technology, occupational therapists need to be aware of the potential for intense emotional responses to the introduction of wheelchairs and other devices into patients’ lives. Such responses may well up, subside, and well up again repeatedly, as with Russell’s phases of resistance and détente. Some persons may need periodic opportunities to express and process these emotions, as when Russell’s therapist took him out for a walk rather than pursuing the planned treatment.

Patients may have functional goals that differ from or are opposed to the goals that seem reasonable to their therapists. Russell’s goal of moving out of a wheelchair, while the therapist tried to help him move into one, is an example of such a goal conflict. Recognition that our goals may differ from our patients’ goals can help lay the groundwork for mutual respect and open communication. Application of one of the most basic principles of occupational therapy—that, to be considered purposeful,
activities must be seen as meaningful by the person involved (American Occupational Therapy Association, 1983), may be extended to equipment provision. A technological device, like an activity, may be accepted only by the person who sees the device as useful for his or her own purposes. Only then can it be seen as a tool rather than an imposition from without. As occupational therapists, we need to recognize that incorporation of new equipment into one's life means not only pragmatic adaptation—which most occupational therapists excel at teaching—but also emotional adaptation, a new self-image and body image that include a splint, a four-pronged cane, or, as in Russell's case, a wheelchair.

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References


