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The Accuracy of New Wheelchair Users' Predictions about their Future Wheelchair Use

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Abstract

Objective—This study examined the accuracy of new wheelchair user predictions about their future wheelchair use.

Design—Prospective cohort study of 84 community dwelling veterans provided a new manual wheelchair.

Results—The association between predicted and actual wheelchair use was strong at 3-months (phi coefficient = .56), with 90% of those who anticipated using the wheelchair at 3-months still using it (i.e., positive predictive value 0.96) and 60% of those who anticipated not using it indeed no longer using the wheelchair (i.e., negative predictive value 0.60, overall accuracy 0.92). Predictive Accuracy diminished over time, with overall accuracy declining from 0.92 at 3-months to 0.66 at 6-months. At all time points, and for all types of use, patients better predicted use as opposed to disuse, with correspondingly higher positive than negative predictive values. Accuracy of prediction of usage in specific indoor and outdoor locations varied according to location.

Conclusions—This study demonstrates the importance of better understanding the potential mismatch between the anticipated and actual patterns of wheelchair use. The findings suggest that users can be relied upon to accurately predict their basic wheelchair-related needs in the short term. Further exploration is needed to identify characteristics that will aid users and their providers in more accurately predicting mobility needs for the long-term.

Keywords

Mobility Disability; Wheelchair; Self Help Devices; Predictive Model; Delivery of Health Care; Statistical Model; Prognosis

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INTRODUCTION

Mobility needs and the ways that a wheelchair will be used to meet those needs are important determinants of the type of wheelchair that will be most helpful and the type of training most beneficial to the wheelchair user. Indeed, the Veteran's Health Administration (VHA) guidelines recommend that wheelchair choice be based on probable duration of use,¹ Medicare policies recommend basing the prescribed mobility aid on anticipated mobility needs² and some third party payers state that a specialized wheelchair is "rarely medically necessary if the expected duration of need is less than 3 months".³ Moreover, the methods for using a wheelchair are specific to the environments in which it will be used and the environment in which the device will be used may in turn dictate some of the needed device parameters (e.g., size, ability to fold the chair for transport, etc). It makes good sense to choose a wheelchair with the anticipated use in mind.

Many studies have examined assistive device use and abandonment.⁴⁻¹⁰ For example, Hoenig and colleagues showed that wheelchair use can be highly variable, even in the first few weeks after receipt.⁷ Cushman and Scherer reported that 36% of wheelchairs had been abandoned 3-months after hospital discharge.⁸ Factors such as impaired mobility, cognitive function, recovery, need for repair/upgrade, specific diagnoses, sociodemographic factors and the extent of the user's involvement in the procurement process have been associated with differences in wheelchair use over time.⁴⁻¹⁰ Despite the numerous studies of the reasons for wheelchair use and disuse over time, we know of no studies that examined the value of patient predictions about their potential mobility needs and related wheelchair use over time.

The lack of empirical data on patient predictions about mobility needs and wheelchair use is surprising in light of the increasing importance placed in rehabilitation on a patient-centered approach to care and the increasing emphasis on evidence-based medicine. Professional opinion is important, but rehabilitation in particular must take into account the patient's perspective.¹¹ The desired outcome in rehabilitation – optimal function – depends on the interface of the patient with his/her environment, and in the case of assistive technology, with the device as well. As addressed in the 2001 revision of the International Classification of Functioning, Disability and Health (ICF), both activity and participation are circumscribed by the environment in which a patient's home and community activities take place.¹² A recent literature review highlighted the common discrepancies between patient and provider perceptions, and their adverse impact on rehabilitation.¹³ Indeed, studies have shown that lack of user involvement in wheelchair selection is an important reason why wheelchairs are abandoned.¹⁰ Tools such as the Assistive Technology Device Predisposition Assessment have been developed with the goal of matching the person to the technology by vesting the user in the process.¹⁴ Review of the literature also noted numerous challenges in employment of patient-centered approaches to care and their limited adoption into clinical practice, due in part to the low-level evidence regarding patient-centered care methods, practices and outcomes.¹³

One approach to this dilemma would be to apply evidence-based medicine methodologies to rehabilitation, using scientific methods to inform providers about "*what data to seek in our clinical examinations and what to ignore ... how to obtain <the data> in a reliable and accurate way.*"¹⁵ An evidenced-based approach to patient-centered rehabilitation might start by using scientific methods to ascertain the reliance one can place on patient-centered clinical information (i.e., mobility needs and anticipated technology use) when prescribing a mobility device.

The goal of this study was to examine predictive accuracy of new wheelchair users about their mobility needs and the ways they anticipated using their wheelchairs, adding to the evidence base on patient-centered rehabilitation for providing assistive technology. The study explored the predictive accuracy by persons newly prescribed wheelchairs as to their future mobility needs according to the aspect of wheeled mobility being predicted (i.e., duration, location and frequency of wheelchair use).

METHODS

Ethics

This study was approved by both Duke University and the Durham Veterans Affairs Medical Center Institutional Review Boards.

Study Design

Secondary analysis of a longitudinal cohort derived from a quasi-experimental study of 2 different methods of wheelchair provision.¹⁶

Study Sample

Eighty-four subjects from an existing database collected as a part of a quasi-experimental trial comparing usual care with an enhanced intervention for providing manual wheelchairs.¹⁶ Subjects were eligible for inclusion in the study if they were patients at the Durham Veterans Administration (VA) Medical Center, had an order by a medical provider for a standard manual wheelchair, were residing in or returning to the community, self-reported that they had not regularly used a wheelchair for more than 1 month in the preceding 12 months, had difficulty walking 2–3 blocks or more, were out of bed for one hour or more per day, had a Short Portable Mental Status Questionnaire score¹⁷ of 6/10 (higher score = better cognition) and provided informed consent.

A detailed description of the original quasi-experimental study can be found in Hoenig et al.¹⁶ In brief, this was a quasi-experimental study comparing subjects provided wheelchairs according to day of the week either through Usual Care or through a novel approach to wheelchair fitting/training. Persons in the Usual Care Group were dispensed a standard wheelchair (K0001)¹⁸ according to normal hospital procedure by a provider (PT, OT, or PT/OT Assistant) without special training in wheelchair provision. Those in the Intervention Group were provided their wheelchairs by a provider (PT or OT) with additional training in wheelchairs, who carried out a structured assessment which was used to individualize the wheelchair prescription, provided additional training and written materials and provided telephone follow-up.

Measures

Questions on wheelchair use were refined from prior studies⁷ with input from providers regarding information typically ascertained during clinical care, including the amount the wheelchair might be used each day and the locations where it might be used. Questions examined in this study included anticipated amount of wheelchair use per day, which we dichotomized for this study as (1) *any* versus *no* use at each time point and as (2) *2 hours/day or less* versus *more than 2 hours per day*. Anticipated locations of use were measured as *any* versus *no* use in the following locations: at home, outside the home, and for specific locations inside and outside the home. Study participants were contacted by telephone at 3- and 6-months to verify their wheelchair use, at which time they answered questions on their actual wheelchair use during the preceding 2 weeks. Sociodemographic and health characteristics were also recorded and are represented in Table 1 of the Results section.

Analytic Methods

The original database included 84 new wheelchair users, 74 (88.1%) of whom had data at baseline on anticipated wheelchair use; data on wheelchair use were available at baseline and 3-months for 55 persons (74.3% of subjects with baseline data), and at baseline and 6-months for 45 persons (60.8%). Conventionally, in survey research, a response rate of 60% allows for generalization of the findings to the sample as a whole,¹⁹ thus, with a sample size of 61% across the three time points we did not impute 3 or 6 month data values for those lost to follow-up. Furthermore, it would have been inappropriate to employ intention-to-treat analytic strategies given the nature of our research questions and subsequent analytic approach. An attrition analysis (chi-sq for categorical and t-tests for continuous) yielded no significant differences on the variables of interest or any of the socio-demographic characteristics for those completing the study versus those who did not.

Since the Intervention Group in the original study used their wheelchair more over the entire study period,¹⁶ our first step was to determine whether the two groups differed according to the primary outcomes for this study. In preliminary analyses, we used the chi square statistic to test whether study group (intervention versus usual care) was associated with any versus no wheelchair use at 3- and 6-months in particular, or with specific locations of wheelchair use at those time points. We found that the Intervention Group was not significantly associated with any/no wheelchair use or locations of wheelchair use at the 3-month or 6-month time points in particular. Data are available from the authors on request with results reported for the two study groups separately.

We examined predicted wheelchair use versus actual use by comparing the proportion of participants in each response category in 2X2 contingency tables. Sensitivity, specificity, positive and negative predictive values and overall accuracy of participant's baseline predictions were calculated for each of the wheelchair use variables. Corresponding phi coefficients were calculated however, because analysis of these data consisted of a series of post-hoc, descriptive analyses and employed multiple independent contingency tables, uncorrected significance tests are not appropriate for inferential interpretation. We report the phi coefficients to provide the reader with an estimate of the degree of association between participants' predictions of use and actual wheelchair use at each point in time.

RESULTS

Eighty-four veterans enrolled in the original study. Table 1 shows that the majority of the veterans enrolled in this study were male (94.0%), white (61.9%), and high school graduates (65.4%) with a mean age of 65. About a third of the sample both lived alone and had an income of <\$15,000 per year. Overall, the population was both ill and physically disabled – over 70% had been hospitalized in the preceding 6-months and on average had 2 or more chronic medical conditions. The most commonly reported medical conditions were cancer, arthritis, heart and lung disease, followed by stroke, fracture and amputation. The study subjects were generally frail, reporting difficulty with 5.0/7.0 Basic Activities of Daily Living (ADLs) and 4.5/7.0 Instrumental ADLs. The most common reasons the subjects reported as causing them to need a wheelchair were weakness (88.1%), poor balance (80.9%) and pain (79.8%).

The majority of participants (79%) anticipated using their wheelchair 6-months or longer and 68% anticipated using it more than 2 hours/day. Over 70% of wheelchair users anticipated they would use their wheelchair inside their home and all of them anticipated they would use it outside their home. As shown in Table 2, 3-months after receiving the wheelchair, 90% of respondents reported that they had used their wheelchair at least once in the preceding 2-weeks, but that diminished to 67% by 6-months. At any given time point,

42% of subjects reported using their wheelchair 2 or more hours per day, 66% reported using the wheelchair inside their home and 92% reported using it outside their home.

Predictive accuracy about future wheelchair use was good in the short term, with a moderate association between the predicted and actual use ($r_p(50) = .56$). However, accuracy diminished over time, with overall accuracy declining from 0.92 at 3-months to 0.66 at 6-months. At all time points, and for all types of use, predictive accuracy was higher for likely use of their wheelchairs as opposed to likely disuse, with correspondingly higher positive than negative predictive values. Patients best predicted any versus no wheelchair use and did relatively poorly at predicting amount of use or location of use, with Phi coefficients as low as 0.16 for wheelchair use > 2 hours/day, 0.34 for wheelchair use indoors and 0.21 for wheelchair use outdoors.

Table 3 shows information on usage in specific indoor locations by assessment phase and across all phases (any use). As with overall use, patients were better at predicting use than disuse with positive predictive values higher than negative predictive values. Interestingly, predictive accuracy for location of use diminished little over time.

With regards to outdoor use, all wheelchair users in this sample anticipated using their wheelchairs outside of the house, so negative predictive value and overall accuracy could not be calculated for those locations. So, we depict the prevalence of outdoor wheelchair usage for various activities across all study phases in Figure 1. Prevalence for outdoor wheelchair usage for specific tasks/locations ranged from 71% for task and errand use to 84.8% for use during medically related outings such as doctor and pharmacy visits, and from 58.8% for activities in the yard to 72.3% for social functions such as visiting a friend or going to church. With prevalence so high, the positive predictive value was correspondingly high. The positive predictive value for any use across study assessment periods was 0.82 for sleeping area usage and 0.83 for medical usage (data not shown).

DISCUSSION

For over 20 years, leaders in the field have reported high rates of abandonment of durable medical equipment and high levels of user dissatisfaction.^{4-10,20} Fifty years ago, choices in wheelchairs were quite limited.²¹ Luckily, choices have greatly expanded^{22,23} and now it is possible to match the type of device prescribed to characteristics of the user and its anticipated uses. However, that in turn requires knowing the user's needs and goals. For some patient populations, future use can be reasonably assumed – for example, a patient with ASIA A paraplegia is highly likely to use a wheelchair permanently and in all locations; whereas, a younger adult whose only illness is a recently fractured leg most likely will not be using the wheelchair permanently and may be able to use crutches in the home. For many patients prescribed wheelchairs, their use is less predictable and highly variable.⁷ Our findings suggest that one of the primary causes of user dissatisfaction and disuse may be a mismatch between the anticipated uses of the wheelchair and the actual use patterns. This interpretation is consistent with earlier findings by Cushman and Scherer showing that consumers have positive expectations for assistive devices and if actual performance falls short of expectations, the response may be to discard the device.⁸

Guidelines from the Veterans Health Administration and third party payers¹⁻³ underscore the importance of considering anticipated wheelchair use to ensure provision of the proper wheelchair. The person who will be using the wheelchair is the most likely source to provide information about his/her own current and anticipated mobility needs. Moreover, the user's perspective is vital to patient-centered provision of care.²⁴ Clinical decisions require a comprehensive assessment which should take into consideration the user's goals and needs.

The ability to take the user's perspective into consideration is enhanced by an understanding of the reliability of his/her estimations. Our study shows that user predictions of future wheelchair use were reasonably accurate in the short term, at the crude level of inside versus outside the home, but less so in the longer term. Accuracy also was lower for specific locations inside and outside the home and for amount of daily use.

Our results have important implications for policies on wheelchair provision. Our study shows that in this mixed population, which included medical/surgical inpatients and outpatients, wheelchair use was quite dynamic. Thus, the Medicare policy of renting a wheelchair by the month makes sense,² but only if there is the opportunity to reassess the patient (e.g., to determine if the patient is exhibiting a need to use the wheelchair full-time and long-term such that a specialized wheelchair may be most appropriate). Our findings indicate that clinical practice for providing wheelchairs might be improved by follow-up contact with the patient at 3- and 6-months to determine if their needs have changed.²⁵ This recommendation is supported in a study by Garber et al suggesting a need for periodic re-evaluation of mobility and psychosocial needs among wheelchair recipients after a stroke and by Demers et al showing highly dynamic.⁶

Policies on wheelchair provision must also consider the ways in which wheelchairs typically are used. High proportions of subjects in this study anticipated that the wheelchair would help them outside the home (70–90% depending on the activity), and indeed a high proportion of subjects used the wheelchair outside the home. Although most wheelchair users anticipated and actually did use the wheelchair in the home (66.6% anticipated, actual 75.0%), wheelchair use was proportionally more common outside the home than inside the home.²⁶ However, Medicare policies in the United States focus solely on use inside the home. Clearly wheelchair use outside the home may be even more important than inside the home, as demonstrated by the high prevalence of use (82%) for medically necessary visits to doctors and pharmacies. In addition to medical necessity, wheelchair use outside the home affects participation in employment-related activities of working age wheelchair users (nearly 80% of whom are unemployed in the U.S.).²⁷

There are several important limitations to consider in evaluating the study results. Some of the subjects received an intervention designed to improve wheelchair provision, which might have affected their predictions about their mobility needs and/or their subsequent wheelchair use. Because the original study did show increased wheelchair use for the Intervention Group,¹⁶ we tested extensively for differences between the two groups in the outcomes studied in this report, and found none, and controlling for group did not alter the study findings on wheelchair use. The original study examined use across all study time points, which maximized study power for inferential purposes. For this study, we focused on particular types of wheelchair use at specific time points. For the 3- and 6-month time points in particular, the original study could have detected a moderate intervention-effect (effect size of 0.25–0.55 with $\alpha = 0.05$). Thus, the likelihood of residual intervention effects influencing the predictive accuracy of these patients at the 3- and 6-month time points is likely modest, but should not be dismissed entirely. Nonetheless, in so far as we did not control for treatment group in our analyses, we cannot entirely rule out the potential effect of the presence of two groups as an 'unmeasured' confounder. Since we used an existing database, we did not calculate sample size or power a priori; and focused on descriptive analyses foregoing formal inferential significance testing. In addition, the measures of wheelchair use were self-reported and have undergone limited formal psychometric evaluation. However, similar measures using recall to assess physical activity have demonstrated acceptable reliability and validity and we have used similar measures in prior studies with good success.^{7,16,28,29}

Generalizability of our findings to our entire study population is appropriate and justified for 3-months wherein we had follow-up on 74.3% of persons with baseline data predicting wheelchair use representing 64.5% of the entire sample, but that declined to 60.8% and 53% respectively at 6 months, so caution should be used in generalizing 6-months results to the entire population of manual wheelchair recipients. Generalizability to other populations is limited to the extent that our study population may not be representative of other populations of wheelchair users. Similar to a nationally representative sample of manual wheelchair users in the United States, this study population was older, poor, the vast majority reported limitations in activities of daily living, and approximately 40% perceived themselves to be in poor health; dissimilarities included a greater rate of hospitalization in the preceding 6 months (73% versus 30%), more men (94% versus 48%), and fewer white subjects (62% versus 85%).²⁷ The most likely reason for the dissimilarities is the study sample being limited to veterans, who have poorer health and worse physical function than non-veterans.³⁰ In addition, the veterans were provided the wheelchairs in the context of the VHA system of care, which differs in important ways from the private sector in the United States, most notably with regards to more liberal provision of assistive technology.³¹ Also, methods for fitting and training persons in use of wheelchairs may differ from those used in our study in important respects. The effects of wheelchair skills training on outcomes is an active area of research.³² Another potential limitation would be expectation bias by the subject, which occurs when the subject's self-report is affected by another objective (e.g., the patient's desire to acquire a wheelchair). Also, the small sample size limits the interpretability and utility of some of our results pertaining to positive and negative predictive power. It will be important to replicate this work with a larger sample and among other populations.

Our goal was a very simple one, to determine the accuracy of patient predictions about their future wheeled mobility in the context of the typical mixed population who may present to clinicians and vendors in diverse settings. So we examined a mixed population of wheelchair recipients and we examined wheelchair use at the aggregate level, combining data from patients who had received a variety of wheelchair types and models. In so far as the extent to which the wheelchairs provided might or might not have been comfortable, easy to use and optimally meets the patient needs, the duration of use might differ for patients provided one type of wheelchair versus another. Moreover, the wheelchair itself may influence duration of use irrespective of its utility, for example, perhaps patients are more likely to retain and occasionally use expensive power wheelchairs compared to manual wheelchairs, or wheelchairs they personally purchased rather than ones provided by third party payers. These are important considerations and worthy of investigation, but understanding all of the factors that may influence wheelchair use over time was not the focus of this study.

In conclusion, the principles of patient-centered care, including the importance of involving patients in their rehabilitation plans, indicate that new wheelchair users should be consulted regarding choices about their wheelchair. Our findings suggest that users can be relied upon to accurately predict their basic wheelchair-related mobility needs in the short term, but that accuracy diminishes when it comes to specific aspects of mobility and over time. Our study shows the promise of understanding users' perspectives in clinical decision-making, but more research is needed to validate these findings with heterogeneous samples. Future work should focus on two areas: (1) determining how user characteristics (e.g., sociodemographic, cognitive, cultural, environmental) influence their goals and their ability to anticipate their mobility needs; (2) studying provider predictions and identifying methods to enhance their ability to predict mobility needs and device use with greater specificity and over the longer term. This in turn will enable health care policy and clinical practices for provision of

wheelchairs (and other mobility devices) to result in optimal mobility and health care cost outcomes.

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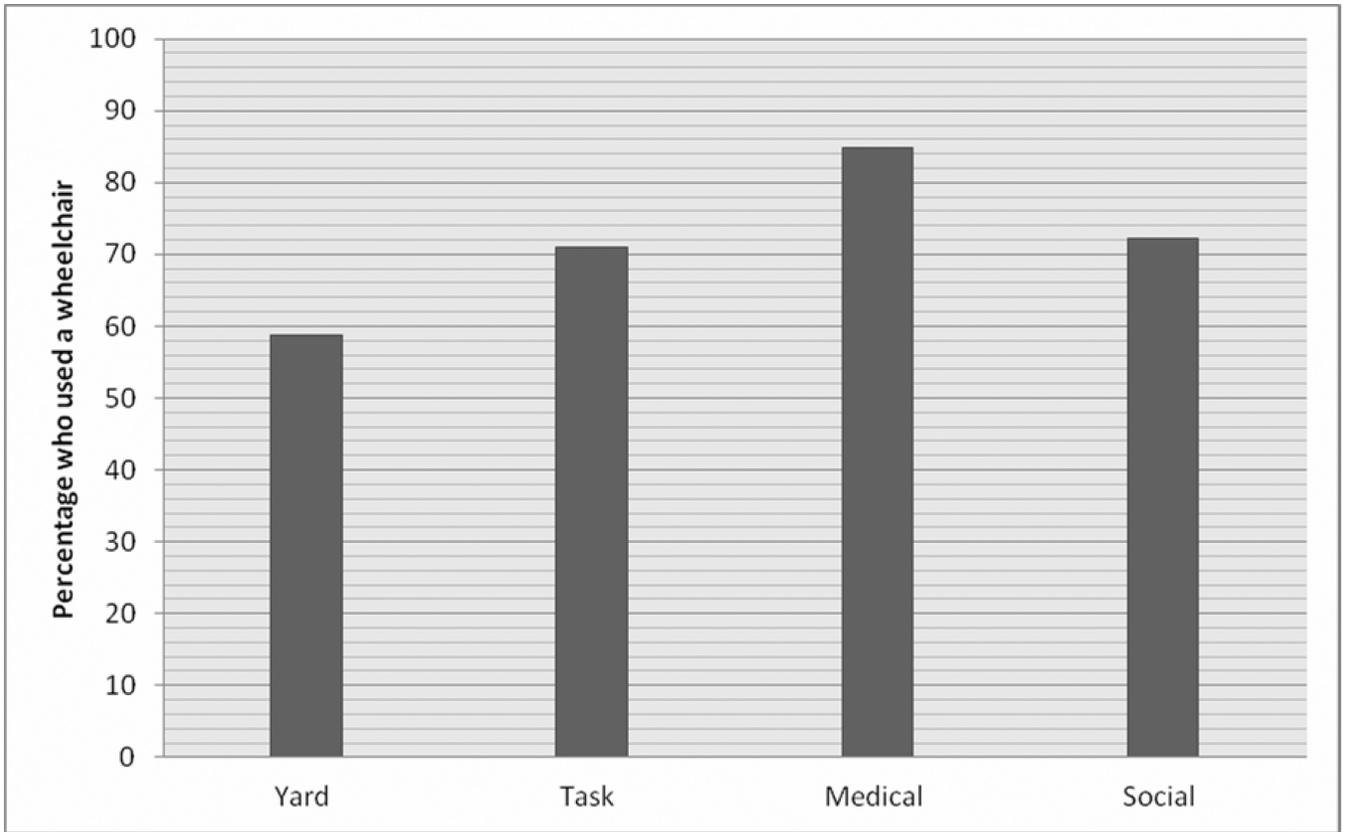


Figure 1.
Prevalence of WC Use for Activities Outside the Home Across all Study Phases

Table 1

Study Subject Characteristics

| Characteristic | N = 84 | % |
|---|-----------|------|
| Sex | | |
| Male | 79 | 94.0 |
| Female | 5 | 6.0 |
| Race | | |
| White | 52 | 61.9 |
| Other | 32 | 38.1 |
| Age, mean±SD | 65.0±13.7 | |
| Education | | |
| Graduated high school | 55 | 65.4 |
| Lives alone | 24 | 28.6 |
| Income <15,000/yr | 26 | 30.9 |
| Overall health | | |
| Excellent | 17 | 20.2 |
| Fair | 27 | 32.1 |
| Poor | 39 | 46.4 |
| Number of chronic conditions, mean±SD | 2.2±1.3 | |
| Number of basic activities of daily living with difficulty, mean ± SD | 5.0±1.8 | |
| Number of instrumental activities of daily living, mean ± SD | 4.5±1.4 | |
| Condition Type | | |
| Heart Disease | 36 | 41.9 |
| Lung Disease | 31 | 36.0 |
| Stroke (ever) | 22 | 25.6 |
| Arthritis | 47 | 54.6 |
| Fracture in the last two years | 13 | 15.1 |
| Amputation (ever) | 8 | 9.3 |
| Cancer (still being treated) | 18 | 81.8 |
| Other neurological issue | 0 | 0 |
| Hospitalized in previous 6 months | 73.8 | 87.9 |

Table 2

Prevalence of specific types of wheelchair usage across study time points along with Positive and Negative Predictive Values, and Accuracy of Prediction for anticipated wheelchair usage compared to actual usage at those time points.

| | Prevalence | Phi Coefficient* | Positive Predictive Value | Negative Predictive Value | Overall Accuracy** |
|---------------------------|------------|------------------|---------------------------|---------------------------|--------------------|
| Duration of Use | | | | | |
| 3 months, n=51 | 0.90 | 0.56 | 0.96 | 0.60 | 0.92 |
| 6 months, n=43 | 0.67 | 0.17 | 0.71 | 0.50 | 0.66 |
| Any Daily Use 2 hours/day | 0.42 | 0.16 | 0.45 | 0.78 | 0.50 |
| Any Indoor Use | 0.66 | 0.34 | 0.76 | 0.91 | 0.82 |
| Any Outdoor Use | 0.92 | 0.21 | 0.96 | NA | NA |

Footnotes:

* The phi coefficient is a measure of the degree of association between two binary variables. This measure is similar to the correlation coefficient in its interpretation.

** Overall Accuracy = (true positives + true negatives/all results).

NA = Not Applicable, since anticipated outdoor use was 100%, the Negative Predictive Value and Overall Accuracy could not be calculated.

Table 3

Usage in Specific Indoor and Outdoor Locations

| | Prevalence | Phi Coefficient | Positive Predictive Value | Negative Predictive Value | Overall Accuracy** |
|-----------------------------|------------|-----------------|---------------------------|---------------------------|--------------------|
| Indoor Use - Toilet | | | | | |
| 2 weeks | 0.37 | .36 | 0.44 | 1.00* | .55 |
| 3 months | 0.59 | .31 | 0.76 | 0.60 | .73 |
| 6 months | 0.53 | .04 | 0.64 | 0.40 | .56 |
| Any Use | 0.62 | .22 | 0.74 | 0.50 | .68 |
| Indoor Use - Bedroom | | | | | |
| 2 weeks | 0.55 | .24 | 0.62 | 0.71 | .64 |
| 3 months | 0.75 | .20 | 0.81 | 0.40 | .73 |
| 6 months | 0.74 | .37 | 0.91 | 0.40 | .75 |
| Any Use | 0.74 | .27 | 0.82 | 0.45 | .73 |

Footnotes:

* The phi coefficient is a measure of the degree of association between two binary variables. This measure is similar to the correlation coefficient in its interpretation.

** Overall Accuracy = (true positives + true negatives/all results).